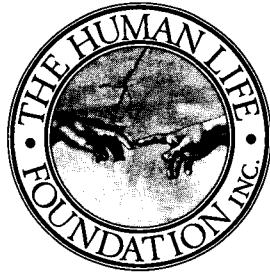


# the HUMAN LIFE REVIEW



WINTER 2004

*Featured in this issue:*

William Murchison on . . . . . Kissing up to Kate

Melinda Tankard Reist on . . . . . Condom Nations

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***Ventilating Life and Death:*** A Symposium

William F. Buckley Jr. • George McKenna • Nat Hentoff  
Rita L. Marker • Francis Canavan, S. J. • Mary Jane Owen  
David S. Oderberg • Stephen Vincent • David van Gend  
and Wesley J. Smith

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***Saving Terri Schiavo:*** Audrey Ignatoff & Vickie Travis

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Mark Pickup on . . . . . Ronald Reagan's Clarion Call

Nicholas Tonti-Filippini, et al. on . . . . 20 Propositions

*Also in this issue:*

Pope John Paul II • Mary Lee Freeman • Joseph Bottum  
Pia de Solenni • Robert Hart

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ABOUT THIS ISSUE . . .

. . . in his remarks at our Great Defender of Life Dinner last October, remarks which inspired the symposium we present in this issue (“Ventilating Life and Death,” page 23), William F. Buckley Jr. reminded his audience that “a half century ago” Pope Pius XII had “counseled . . . against the use of what he called ‘heroic therapy’ to prolong life.” Buckley wondered if “such thought as gave rise to the factor of moral qualification” could “apply today, a fortiori, to life that goes on, unwelcome by everyone, imposing great strains on the medical community, and strains also on family and beloved friends who need to act as though the insensate person were still with them, an active member of the family, though such is not the case?”

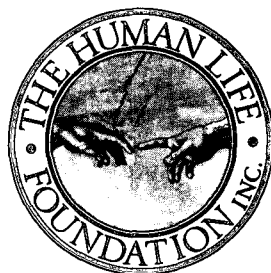
It’s interesting to note that when Pius was addressing medical conferences in the ’50’s, there was concern about whether the use of technological advances like ventilators and even anesthesia might undermine Catholic teaching on the need to accept suffering and death. Today, the discussion has undergone a shift. Pius observed that “*one is not forbidden* [our emphasis] to take more than the strictly necessary steps to preserve life and health, as long as he does not fail in some more serious duty.” Pope John Paul II, in a recent address (page 110) seems, at the very least, to be enhancing the definition of “strictly necessary steps”:

However, it is not enough to reaffirm the general principle according to which the value of a man’s life cannot be made subordinate to any judgment of its quality expressed by other men; it is necessary to promote the *taking of positive actions* as a stand against pressures to withdraw hydration and nutrition as a way to put an end to the lives of these patients. It is necessary, above all, *to support those families* who have had one of their loved ones struck down by this terrible clinical condition. They cannot be left alone with their heavy human, psychological and financial burden. [Emphasis in original.]

Like his teaching on the death penalty, which asserts that advanced societies can and should protect themselves from dangerous criminals without executing them, the Pope insists here that such societies must also assume the burden of caring for their profoundly disabled members—a position which puts him at odds with the growing utilitarian “culture of death,” as he was the first to call it several years ago. At odds also, perhaps, with a generation of Americans who are finding it hard enough to care for aging moms and dads who retain all their faculties.

Dr. David van Gend told me in an e-mail that commenting for our symposium was more difficult than he had thought it would be. We thank him and all of our other participants for their enlightening contributions on a subject which is not, at least emotionally, as clear-cut as abortion. And thanks again to William Buckley for, in his words, “speak[ing] out loud thoughts I don’t doubt many of you have had, but perhaps not so many have expressed.”

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## INTRODUCTION

**W**E BEGIN OUR THIRTIETH straight year of publishing with the signature straight-talk of our esteemed Senior Editor William Murchison, who describes the assault on the senses of an election year: "I am talking about junk and nonsense and equivocations repeated over and over again for maximum effect." Contemporary political culture is about "shunning the complex," reducing great grave questions to "sound bites and happy talk." Including "our" question: "Again in 2004, presidential politics is reducing the human life question—the terrible, terrifying question, the question of all questions in some sense, to bumper sticker material."

And the *mandatory* slogan, the one that commands 100% support from any serious Democratic presidential candidate, is a "woman's right to choose." As Murchison writes, Democrats who would like to be president "are in bondage to the pro-choice movement." John Kerry has not only kept in line, but distinguished himself as a pro-abortion politician, consistently voting against the partial-birth abortion ban, and recently, against the successfully passed Unborn Victims of Violence Act. Voting for abortion is not compatible with Kerry's professed Roman Catholicism but, as Murchison points out, politicians like Kerry have a primary allegiance:

Since *Roe v. Wade*, one discovers, a colossal switcheroo has taken place. The role of guardian of truth has devolved upon NARAL Pro-Choice America, which has its own college of cardinals, not to mention female pope, the latter of course being Kate Michelman. No belief, no conviction unless vetted and approved by the sacred consistory of NARAL may be heard in the land without shame. . . .

We find a more global report on the new "guardians of truth" in our next article, "Condom Nations." Melinda Tankard Reist, who writes from Australia, reports on a BBC television program, "Sex and the Holy City," which blames the Catholic Church for the Third World's poverty and disease. Why? Because the Church is against reproductive rights and the use of condoms, of course. Tankard Reist exposes the blatant anti-Church propaganda of this television show, and presents the *facts*. Women and children are dying in droves from diseases such as tuberculosis and malaria, which are preventable with

good hygiene and antibiotics but, as Reist writes, “money has been siphoned off from basic health needs such as safe water, sanitation, vaccinations, nutrition and antibiotics and put into population programs. Even in some of the remotest corners of the world, health workers are reporting surpluses of contraceptives, while they have no antibiotics to treat infection.” Spreading the gospel of “family planning” in the Third World is creating orphans, and perpetuating cycles of poverty and disease. Similarly, the nations with the most condoms thrown at the AIDS epidemic are *not* the nations in which the AIDS rate is falling. There is a remarkable story about Uganda, which once had the highest rate of HIV infection in the world; it has now achieved an unheard of decline due to a national program stressing abstinence and fidelity. While this program has been scoffed at by the health-care elite, it is saving many lives—as do countless programs run by the Catholic Church, which is the “largest provider of health care and education to women and children in the world.”

And now to “Ventilating Life and Death,” the symposium which appears in this issue. As Anne Conlon informed you in her last publisher’s statement, we didn’t include William F. Buckley Jr.’s remarks in the special section we ran on our Great Defender of Life Dinner because we’d asked several contributors to comment on them. Mr. Buckley’s remarks were unexpectedly provocative, and were framed as a challenge to our *Review*. He asked “whether the present company, in particular the gifted editors and contributors to the *Human Life Review*, oughtn’t to ventilate another concern, this one having to do not with the beginning of life, but with its ending.” As you will see in the responses gathered here, Mr. Buckley’s invitation prompted a rich and important discussion. Our participants include a stellar list of *Review* contributors (four of whom were at our dinner): George McKenna, Nat Hentoff, Rita L. Marker, Francis Canavan, S.J., David S. Oderberg, Stephen Vincent, David van Gend and Wesley J. Smith. We also welcome a newcomer to the *Review*, Mary Jane Owen, who is director of the National Catholic Partnership on Disability.

Mr. Buckley’s remarks are well covered by our host of distinguished contributors. As your editor, I would like to add just a few points. First of all, the obvious: *Review* editors and contributors *have* been discussing end-of-life issues from the very beginning of our publication and throughout our almost 30-year history. Mr. Buckley must know this. He was my father’s boss at *National Review* during the founding days of the *Review*—it would be correct to say there might not have *been* a *Review* without his remarkably generous encouragement and support—and he has read the *Review* from the beginning. So, it seems to me that his challenge has more to do with his concern over the moral quandaries that technology has created in end-of-life care; specifically, as he mentions, in cases where a person seems “insensate.” He also appeared to be appealing to us not to be “so pro-life” that we forget that even the Catho-

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lic Church does not require extraordinary means if they are considered too burdensome, and that life at all costs is not the ultimate goal.

A fair point to make perhaps; but issuing such a caveat to our gathering was unsettling. After all, it is the secular media's agenda to portray members of the pro-life movement as religious extremists, with a "fetish" about life, and a dearth of compassion for actual people. The *reality* is that the great majority of those who fight for the protection of human life in our culture, including the Catholic Church, approach end-of-life issues with discernment, intelligence and gravity. And the bottom line, as expressed by Father Francis Canavan and Professor David Oderberg, among others, is that the prejudice *against* life in contemporary bioethics has gotten so extreme that worries about being "too" pro-life greatly pale in comparison.

A point of contention, as you'll see, came about because Buckley made a remark in passing referring to the case of Terri Schiavo, although he did not mention her by name. He seems like many Americans to have been unaware of the full story—the result of the major media's "take" on the facts. But many of us at the dinner were painfully aware of Schiavo's plight, most especially Rita Marker (she responds on p. 36), who had been one of the many working tirelessly to save Terri's life. Just two days before our dinner, Schiavo's feeding tube had been removed by court order, against the wishes of her parents; on October 17 she was being starved and dehydrated. (As our readers know, Schiavo's tube was reinserted on October 21 due to the intervention of Florida Governor Jeb Bush and the Florida legislature.) In the case of Terri Schiavo, one question is whether or not her artificial nutrition and hydration, i.e., feeding tube, constitutes ordinary or extraordinary care, and we have much discussion of this subject in our pages.

On the evening of the dinner, we were also honoring the fifth anniversary of my father J. P. McFadden's death. He survived his last five years thanks to feeding *and* tracheal tubes; while he suffered greatly because of his illness, he lead an active life until the end, dying, as a matter of fact, just twelve hours after returning from a full day at the office. A difference between Terri Schiavo and J.P., is that Schiavo, while not terminally ill, is severely brain-damaged and cannot communicate. My father's body was failing, but his mind remained razor sharp. J.P. could make decisions and feed himself; Schiavo is dependent on others. For most of us, there is terror in imagining being kept alive after our mind no longer works; or of being helplessly dependent. Likewise, standing by a loved one who appears to be, in ways that matter, already dead must seem at times unbearable. But morality cannot be decided on feelings, or on hard cases, even when they are terrifically hard. As J.P. himself argued (in "Toward the New Future," *HLR*, 1983) one cannot try to straddle the two warring ethics of our culture—sanctity of life vs. quality of life: one must *choose*. The *Review* will continue to defend the sanctity and intrinsic dignity of *all* human life, regardless of age, illness, or cognitive impairment.

The symposium themes are further developed in our last three articles. In the first, we hear from Audrey Ignatoff and Vickie Travis, two women who were part of a present-day “underground railroad”—a “wild ride” on the Internet, which gathered steam as supporters of Terri Schiavo urged others to climb aboard and work to save Terri’s life. An international network known as “Terri’s Angels” was formed, and was a powerful force in bringing about Terri’s Law, signed by Governor Bush on October 21. This fast-moving account, by women who are activists for health-care reform, brings out a crucial point of the Schiavo story: many states, including Florida, have laws already on the books to protect vulnerable adults from abuse at the hands of their guardians. The actions of Michael Schiavo ought to have warranted legal intervention *before* he asked for Terri’s feeding tube to be removed, and that was a driving force in the effort to persuade Governor Bush and the Florida legislature to act on her behalf.

The case of Terri Schiavo, as Mark Pickup writes next, has historical parallels to the “Baby Doe” case in 1982, in which an infant with Down’s syndrome was starved to death, at the behest of his parents, and despite the many people who came forward to adopt him. Pickup writes about the case, and the article written six months later by then President Ronald Reagan for the *Human Life Review* (a stunning moment in our *own* history). In “Abortion and the Conscience of the Nation,” Reagan cited the Doe case as a tragic confirmation of the harm legalized abortion had unleashed: “We cannot diminish the value of one category of human life—the unborn—without diminishing the value of all human life.” He wrote: “The real question today is not when human life begins, but *What is the value of human life?* . . . Obviously, some influential people want to deny that every human being has intrinsic, sacred worth.” As Pickup observes, little did Reagan know that, a decade later, he would be facing his own debilitating illness; he recalls the grace and courage with which the former president announced that he had Alzheimer’s, and his appeal to Americans to support those families enduring the painful journey of losing a loved one to the ravaging disease.

When we asked contributor David van Gend to join our symposium, he introduced us (through e-mail) to a friend of his, Australian ethicist Nicholas Tonti-Filippini, who was about to present a paper on the withdrawal of artificial nutrition from persons in “vegetative” states at an international Catholic Congress in Rome. Dr. Tonti-Filippini and his co-authors have kindly revised their paper for the *Review*. “Twenty Propositions” is their “attempt to clarify” the discussion and so “foster agreement within the Catholic tradition”; they also speak directly to the issues raised in our symposium. There is much discussion in “Twenty Propositions” on the question of human dignity, which, in the Church’s view, is “inherent, it cannot be lost and is not dependent on capacity.” Essential dignity is “connatural”: “it is this notion of dignity that results in us upholding respect for human life from beginning as an embryo

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without evident ability to think, throughout all stages, whatever happens, and until the end of life, even though for some the end of life is preceded by a phase of lost intellectual ability.”

\* \* \* \* \*

We begin our appendices with the address Pope John Paul II gave at that Rome congress. The Pope points out the difficulty in predicting with certainty whether or not a person will remain in a “vegetative” state, and then rejects the term itself: *A man, even if seriously ill or disabled in the exercise of his highest functions, is and always will be a man, and he will never become a “vegetable” or an “animal.”* Death by starvation or dehydration, the Pope says, ends up becoming “euthanasia by omission.” In *Appendix B*, we shift from theory to reality: a wrenching account of the realities for families at a hospice center. In “Caring for the Dying,” hospice nurse Mary Lee Freeman offers a poignant reflection on her work, where she is “a participant observer in thousands of final scenes.” She believes that “if we consider ourselves masters, rather than stewards” of our lives, then death and dying are the “ultimate indignity.” But “acceptance of the human condition—not horror at its indignities—is the best way of combating the influence of those who feel compelled in their own well-meaning way to hasten death’s arrival.”

We return to the subject of abortion in our last appendices. *The Weekly Standard’s* Joseph Bottum tells an important story of leaked internal memos from the Center for Reproductive Rights, a non-governmental organization (NGO) which specializes in “suing local and national governments that fail to allow unfettered access to abortion.” These memos were mailed anonymously to Austin Ruse, president of the Catholic Family and Human Rights Institute, and, as Bottum explains, they make for fascinating reading because “they show how NGO activists speak behind closed doors.” In *Appendix C*, Pia de Solenni reports on Congressional hearings (held in early March) on abortion’s impact on women. Pro-choice members of Congress were not listening, she says: “not one [abortion] advocate would admit the importance of research on abortion and its effects on women, a strange fact considering that they argue in behalf of women’s health.”

We like to provide our readers with some light-hearted respite from the grave issues we discuss in our pages; we’ve included a few inspired cartoons from our friend Nick Downes. And we close the issue with a beautiful, uplifting piece by an Anglican priest, the Reverend Robert Hart, which illustrates that “hard cases” not only ought *not* to become an excuse to abandon principles, but may become, through the mysterious goodness of God, opportunities for abundant grace and even joy. Until next time . . .

MARIA MCFADDEN  
EDITOR



## Kissing Up to Kate

*William Murchison*

The challenges of a presidential election year—this one, for instance—are many and varied, such as the likelihood of being prodded by that pesky old conscience to tune in a televised presidential debate. Maybe good old morbid curiosity does the job. Either way, stoic patience is the watchword, not just for the candidates who exhibit their stuff but also for the voters they seek to overhaul, wheedle, and persuade. And by the way, would the late Marcus Aurelius himself be up to one of these quadrennial exercises? He was an emperor, after all, with small disposition probably to suffer fools longer than it took the Praetorian Guard to hustle them away.

In a presidential year, there is much the voters must bear with, nor am I talking about advertisements alone. I am talking about junk and nonsense and equivocations repeated over and over again for maximum effect. Pitching your message at nearly 300 million not-exactly-like-minded citizens means, among other things, shunning the complex, hunting for the hot button, declining to see both sides of a question (unless, to be sure, you miraculously discover three or four sides, each worth discussing to three or four distinct audiences). Great grave questions reduce to sound bites and happy talk. You wouldn't like to imagine, probably, how the likes of Madison must be taking it in, their wool-stockinged legs crossed in some celestial retiring room for founding fathers.

Again, in 2004, presidential politics is reducing the human life question—the terrible, terrifying question, the question of all questions in some sense, to bumper sticker material. There will be no careful, reasoned debates this presidential season, over the imputed rights and the imputed wrongs. There will be as usual shrieks, most of which will proceed from the liberal and Democratic side of the political spectrum.

Kate Michelman of NARAL Pro-Choice America emitted one notable shriek on Jan. 22, 2004, the 31st anniversary of *Roe v. Wade*. She was in a mood for fund-raising and brow-beating. “[W]e are truly at a moment,” said our Kate, “in which American women could again be stripped of their rights and forced into deadly back alleys.” Really? Well, really, according to a pro-choice leader who wants to make sure her pro-choice political Indians stay close to the reservation. As of course they will, if they know what's good for them.

Political discourse on abortion is generally worse than unenlightening. It

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William Murchison is Radford Distinguished Professor of Journalism at Baylor University.

is off-putting and useless, save in terms of rousing the troops. It must be acknowledged that the pro-life side of the equation doesn't necessarily, by virtue of alignment with the moral tradition of Christian civilization, produce the most delicate rhetoric. Nonetheless, the most stubborn talk, the most adamant, tends to come from national Democrats, a not-quite wholly-owned subsidiary of the pro-choice movement. (Union chieftains and minority "spokesmen" like Al Sharpton enjoy co-ownership rights.)

Democratic presidential candidates can't blow their noses without making the noise sound like a honk of approval for the proposition that a woman has the right to "choose."

News of this nature is not news to readers of the *Human Life Review*, or to most other sentient voters. Why bring it up again? Does bringing it up equate to mere dead-horse-beating? Actually, I think not. There is some use and merit in, from time to time, traversing familiar terrain for the sake of remembering how the land lies—irrespective of the way it ought to lie. The Democratic party, and of course those leading Democrats who would like to be president, are in bondage to the pro-choice movement.

What the movement says, goes. What the movement says is, roughly speaking, a woman's body is her own; so keep hands off if you're a lawmaker or judge. The Democratic candidates comply. They know, or sense, the cost of defying the likes of Kate Michelman, abortion absolutist, whose look can kill, politically speaking, from 3,000 miles distant. You clearly don't want one of Kate's looks. You want her vote. So you fall over yourself trying to please—assuming you really, truly, want to be president of the United States. You give no quarter to doubts. You click your heels smartly.

If you see the point of pro-life protestations and execute some nods in that general direction, your nose starts to pick up the odor of cooked goose, coming from the Michelman kitchen.

Richard Gephardt had that experience. In the '80s, Gephardt, then a mere Missouri congressman, was generally pro-life. He wanted to be president. For that to happen, certain philosophical adjustments were indicated. They took place. Richard Gephardt became pro-choice. Would he have become pro-choice in any case? Sincere conversions do occur, as St. Paul and St. Augustine would testify were they available. This conversion, nonetheless, had the look and smell of raw opportunism.

Gephardt, in 2004, fell early from the running. His conversion had cleared no certain place for him at the Democratic table. Plenty of other pro-choice Democrats had pulled their chairs up, jostling Gephardt for the seat nearest Kate Michelman. No Democratic presidential candidate held back, not even the Rev. Al Sharpton, whom you might not unreasonably have expected to

cut a little more slack for biblical authority and Christian tradition than more secular types like . . . well, like Howard Dean would have.

Dean, the Episcopalian who became Unitarian due to a dispute with his church over an aborted bicycle path, does find the principle of abortion to his liking. While governor of Vermont, he proposed, as part of a healthcare reform, that the state offer \$5 abortions to poor women. There seems in retrospect a whiff of eugenics to the Dean proposal: more abortions for the poor, fewer poor kids born into the world to consume government services and pollute the gene pool. Maybe that is leaning too hard on Dr. Dean, but then his sympathies for babies partly extracted from the womb, then drained of their brains, are not conspicuous.

The good doctor, back when he was a hot presidential property, affirmed a mother's right to decide for herself about abortion, in consultation, if she liked, with parents and doctors. "[M]aking personal medical decisions for Americans," he brusquely declared, is "none of the government's business."

Oh? And why is that? Is some explanation owed? Evidently not. The decisive question, as Dean professed to see it, is "deeply personal." That would seem true, and also worthy of examination in policy terms provided some "personal" standing were conceded to unborn babies: some expectation of a right, on their own side, to life, liberty, and the pursuit of Pell grants.

How can you not have such a debate in an election for the most powerful secular office on earth? You could, technically, of course, but not without riling up the pro-choice side.

Gen. Wesley Clark, during his candidatorial heyday, showed himself hep to the challenges at hand. Clark told the editorial staff of the Manchester, N.H., *Union-Leader*, that he wasn't "going to get into a discussion of when life begins." From the standpoint of his audience outside the office of the conservative *Union-Leader*, this was entirely prudent. Discussions relating to the start of life lead inevitably to the question: What obligations upon individuals and society does the start of life entail? Isn't life traditionally entitled to protection?

That wasn't the discussion in which Clark wanted to engage. What he wanted was to declare solidarity with Kate Michelman. He succeeded. "I'm in favor of choice, period, pure and simple," the general snapped back. "You don't put the law in there." No law? No law at all? The *Union-Leader* staff afforded the general opportunities to retreat from that exposed position before logic overran his flank. He stood fast. *J'y suis, et j'y reste* the French marshal said. Here I am, and here I stay. You get medals that way sometimes. Not this time. Word got around that Gen. Wesley Clark, by the logic

of his own reply to a question, seemed to favor abortion in every case the woman wanted it. This was, ahem, sticking out the old neck pretty far. (ABC pollster Gary Langer notes that whereas most Americans think abortion “should be generally available . . . most do think it’s generally objectionable and as such shouldn’t be done casually or as a mere convenience.”)

Bugler, sound retreat! Cogitation led to clarification. The general supports *Roe v. Wade* “as modified by *Casey*,” the Supreme Court decision that created some hard-to-define rights when it came to protecting unborn life. NARAL Pro-Choice America understood.

NARAL Pro-Choice America’s writ (and of course that of non-affiliated abortion supporters) runs right up to the door of the church. Neither scripture nor the authority of the church has Kate Michelman’s clout with the Democratic presidential stable. Wesley Clark turns out to be a Roman Catholic. As everyone knows, Roman Catholicism and its pope strenuously, uncompromisingly, oppose abortion. That would seem to argue, would it not, Gen. Clark—an interviewer put it to him in these terms—for a different stance on abortion than one of total, or near-total, approval. Well, you see, the general replied, “I understand what the Catholic doctrine is. But I have freedom of conscience . . . [A]s much as I respect the opinion of the Catholic Church, in this case I don’t support it.”

It is not the kind of observation one passes over with gingerly tread. The doctrine of the church, in Wesley Clark’s telling, has become the “opinion” of the church—suddenly a very mortal thing, a human thing. Opinions are variable. We all have them. That’s not to say we should enforce them. To attempt such a thing, don’t you see, would be brutal, undemocratic, a violation of the sacred right to privacy. We are all so very private around here, it seems, that no one has the right (no political right, that is) to elevate one private judgment above another.

Of course Clark didn’t put it that way. Why should he have? He merely wanted to extricate himself from a theological discussion—the kind of discussion few generals, certainly few Democratic generals hopeful of becoming president, go in for these days.

I tease out the implications of Clark’s weasel-out to highlight the kind of dishonesty the abortion lobby is enforcing on the leadership of one of our two major political parties. The abortion lobby won’t tolerate a dissenting opinion. You wonder where the leaders learned this approach. In a Saudi madrassa? Well, anyway there it is. If you want the Democratic nomination for president of the United States, get used to how things are.

You certainly get the impression that theology doesn’t rate highly with leading Democrats and pro-choicers. This comes of seeing theological teaching

quickly reduced to mere opinion, such as any pimply devotee of Britney Spears might venture. You'd have no idea the teaching about respect for unborn life rests on anything other than medieval misogyny or some such.

Opinion. Ah, yes.

But occasionally, from a candidate, comes a hint of larger understanding. Such a hint can tantalize, as in the case of John Kerry, ahead of whom at last lies an unobstructed trail to Election Day (though not necessarily beyond). Kerry is an ex-altar boy who once contemplated the Roman Catholic priesthood. "Whatever my personal beliefs," he told a South Carolina audience after the New Hampshire primary, "they have no place here." See—the barest suggestion, hardly breathed, that, possibly, conceivably, Kerry the Catholic boy all grown up, could see some merit in the church's established position on unborn life. That's as far as heresy goes in the Reformed Church of Choice: a wink; make sure that's all.

Since *Roe v. Wade*, one discovers, a colossal switcheroo has taken place. The role of guardian of truth has devolved upon NARAL Pro-Choice America, which has its own college of cardinals, not to mention female pope, the latter of course being Kate Michelman. No belief, no conviction, unless vetted and approved by the sacred consistory of NARAL may be heard in the land without shame. As for the shameful—those pro-life Galileos rash enough to challenge the cardinals: Toll the bell! Close the book! Quench the candle! Let them be anathema!

Anyway if they have any notion of uniting Democrats behind their presidential candidacies.

Pro-choice leaders' obsession with presidential politics, and the Democratic presidential candidates' forelock-tugging in the presence of these leaders, seems to have at least two sources.

One is unease as to the reliability of the Democratic troops on Capitol Hill—their capacity for slacking or even mutiny. When the rank and file can't necessarily be counted on to march on command, and without muttering, the question of who gives the orders takes on some urgency.

Last year's congressional battle over partial-birth abortion—which issued in passage of the first federal bill ever to criminalize an abortion technique—crystalized the challenge facing pro-choice leaders such as Michelman. Seventeen Democratic senators voted for the bill, as did two-score House Democrats, including five from Al Gore's Tennessee. Even Senate Democratic leader Tom Daschle voted yes, avowing that "[W]e've got to address this issue and let the courts decide . . ." Well, uh-huh; still, a yes vote is a yes vote. Democratic Sen. Blanche Lincoln, describing herself as "about 99 percent

pro-choice,” likewise voted yes, attributing her decision to the popular will back home, in Bill Clinton’s Arkansas. The final Senate vote was 64-36; in the House it was 282-139.

Naturally disloyal doubts about partial birth abortion didn’t afflict John Kerry, who objected—for public consumption at least—to the lack of an exception in the bill for protection of the mother’s health (the same grounds cited by President Clinton when he twice vetoed bans). Kerry has since referred to the ban as “a dangerous effort to undermine a woman’s right to choose.” For the same ostensible reason Sen. and sometime presidential candidate Joe Lieberman likewise voted no. In time past Lieberman, the most faith-oriented of the Democratic presidential candidates, has branded partial-birth abortion “horrific”—while perpetually voting not to ban the horror. John Edwards’ was one of two Senate votes not cast on this occasion.

Despite such evidences of loyalty to the cause, Kate Michelman gazed out bleakly upon the chaos of the battlefield. “Politicians,” she reported, “got nervous.” No doubt. Pro-lifers had turned the pro-choice flank through relentless presentation of the realities involved in the medical “procedure” known as intact dilation and extraction, i.e., the suctioning out of fetal brains to facilitate abortion. If Congress today can assert itself with such unusual effect, what might it do tomorrow? Michelman voiced suspicions regarding a plot “to take away entirely the right to personal privacy and a woman’s right to choose.”

That brings up prospects, such as they are, for replacement of the next U.S. Supreme Court retiree (Sandra Day O’Connor? John Paul Stevens? Chief Justice Rehnquist himself?) with a jurist friendly to maintenance of the *Roe v. Wade* regime. As Michelman warned on the most recent anniversary of *Roe*, “Anti-choice momentum is growing . . . The extreme conservative leadership that controls both houses of Congress is committed to taking women’s rights away. The Supreme Court may be no more than one vote away from hollowing out *Roe* or two from overturning it completely.”

The last thing Kate Michelman probably could be called is complacent. Efforts to calumniate, then eliminate, Republican nominees to the federal bench have received the pro-*Roe* faction’s complete and earnest attention for months now. The idea, evidently, in smearing able appointees to the lower courts (e.g., Miguel Estrada) is to show what lies in store for any candidate whom President Bush, if re-elected, might name to the court without advance approval from NARAL Pro-Choice America. Watch out! is the watchword. You think Clarence Thomas and Robert Bork had it rough! Wait and see what happens to any high-court nominee viewed as dwelling to the right of David Souter.

How much easier, all the same, to be rid entirely of Bush, who gratefully signed the partial-birth ban, and whom Maria Gallagher, of *LifeNews.com*, calls possibly “the most pro-life president of the post-*Roe* era.” The horror, the horror! Better to oust such a guy than exhaust yourself, and your cash reserves, working everlastingly to control him. All the more to the point this seems, given the exponential growth (as of this writing, in March) of Bush-Hating as a popular pastime and a possibly decisive factor in the presidential election. A pro-choice Democrat in the Oval Office—he could be pro-French and pro-tax hike, as well, without impairing Kate Michelman’s aims—would presumably always do “the right thing”; nor would one have to threaten him, or wait expectantly while he recalled the side on which his bread was buttered. He would know in his heart what his friends expected of him.

It is easy enough to imagine a President Kerry vetting judicial nominees with NARAL Pro-Choice America in the interest of—you know—fairness and the defense of constitutionally embedded rights. Another Bill Clinton would do just fine. For all the former president’s “safe, legal, and rare” talk, the need to make abortion truly rare seemed the last consideration on his mind. He did just fine from the pro-choice viewpoint: a friend to those who needed one.

On marches Clinton’s party, arm in arm with the likes of Kate Michelman. No rupture seems likely in the mutual dependence society the two have formed, a dependence far stronger than that which is said to link Republicans and the “religious right.”

Without firm, monolithic Democratic support, the absurdities of the *Roe v. Wade* regime are likely, in some measure, to meet with political and judicial rebuke. Without the support of the abortion lobby, no Democrat seems able to procure the presidential nomination, or anything else at the national level. Retiring Georgia Sen. Zell Miller appears the exception that proves the rule.

We know how the dependency culture is viewed in therapeutic circles. The partners need each other, can’t live without each other, encourage each other in ways destructive as well as constructive. The partial birth debate suggests at least one means of breaking (at least occasionally) the iron circle: namely, exhibit the horror and don’t ever stop, no matter what.

Because . . . because, indeed, of many things: the sacred character of human life; the aggressive character of the abortion regime; and, yes, the arduousness of the journey to this political halting place, where the suctioning of baby brains has been put outside the law. For now.

# Condom Nations

Melinda Tankard Reist

**T**here are a lot of street kids in the Philippines. Nicaragua is a macho country. Poor people live on railroad tracks and garbage dumps. Women are treated violently. Cities are overcrowded. AIDS is killing millions. Some men tell their girlfriends they won't get pregnant if they use Colgate toothpaste.

Whose fault is all this? The Catholic Church's of course.

*Sex and the Holy City*, a BBC Panorama Program broadcast on BBC World late last year, blamed the Catholic Church for a vast array of bad things. It featured the adventures of a white Anglo-Saxon male, Steve Bradshaw, traipsing around the world hunting out victims of Catholic superstition and ignorance.

The Church's opposition to abortion and contraception had "deprived millions of women of the right to control their fertility—at a time when many have begun to see this as a key to development and eradicating poverty," Bradshaw intoned. Yes, it's that simple. It all comes down to the delinquent wombs of women whose childbearing is to blame for the state of the world as we know it.

There was no mention of the structural reasons behind poverty: Forced collectivisation of land, unsustainable farming practices, consumerism, militarism, and inequitable distribution of wealth and resources are all ignored in Bradshaw's simplistic—and typically Western—conclusion that it is women breeding "like rabbits" that causes universal suffering.

Nor did Bradshaw point out that money has been siphoned off from basic health needs such as safe water, sanitation, vaccinations, nutrition and antibiotics and put into population programs. Even in some of the remotest corners of the world, health workers are reporting surpluses of contraceptives, while they have no antibiotics to treat infection. Meanwhile, major diseases continue to run rampant.

Tuberculosis is now the single biggest infectious killer of women in the world.

According to new research from the World Health Organisation, 900 million women worldwide are infected with the disease. It accounts for nine percent of deaths among women between the ages of 15 and 44. No other

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infectious disease creates so many orphans. “Wives, mothers and wage earners are being cut down in their prime and the world isn’t noticing,” says Dr. Paul Dolin of WHO’s Global Tuberculosis Programme. “Yet the ripple effect on families, communities and economies will be felt long after a woman has died.”

Malaria causes more than 300 million acute illnesses and at least one million deaths annually, accounting for one in five of all childhood deaths in Africa. Diarrhoea is estimated to be responsible for 12 percent of the deaths of children under five years of age in developing countries—and a total of 1.3 million deaths each year.

According to the World Bank publication, *Making Infrastructure Work for the Poor*, “the numbers of ‘infrastructure poor’ people are vast in every region of the developing world. Some 1.2 billion people currently lack access to safe, potable water, making them vulnerable to water-borne illness. Inadequate sanitation for 2.4 billion people means they are having to live in degraded environments where disease can easily spread. An estimated 2.5 billion remain without access to modern energy supplies, often meaning no light for studying or learning and only dirty fuel to burn for heating and cooking (leading to respiratory illness).”

But these needs remain unaddressed. As Indian feminist activist Dr. Mira Shiva once said: “We’ve got the right to contraception but we haven’t got the right to eat. What does choice mean for women who don’t have basic food? The question of the basic needs of the poor does not come onto the agenda.” But you didn’t see Dr. Shiva on Bradshaw’s show.

Dr. Junice Melgar, working in the Philippines, claimed in *Sex and the Holy City* that the church is opposed to “reproductive health care” and is causing women to die. The fact is that the Church is the largest provider of health care and education to women and children in the world, including a much greater contribution to maternal health programmes, fertility awareness programmes and anti-poverty programmes than any of its critics.

It is time the real causes of maternal mortality were recognised: respiratory diseases, parasitic infections, poverty, malnourishment, the lack of pre-natal and post-natal care, chronic shortage of trained midwives and centres equipped for obstetric complications. Studies indicate that most maternal deaths could be avoided by adequate basic health care. The UNFPA *State of the World Report* (2002) shows that maternal deaths in sub-Saharan Africa have not fallen since 1990. While untold amounts are spent on “family planning,” the underlying causes of maternal mortality remain unaddressed.

If contraception and abortion are the answer to poverty, why have countries in some parts of Latin America and Asia—where vast numbers of women

have been sterilised—become poorer? It is very easy to shove contraceptives down a woman's throat or into her arm or uterus. It is another thing to deal with the underlying causes of women's ill-health. In an article titled "Reproductive Health and Human Rights" in *The Lancet*, Adrienne Germain, president of the International Women's Health Coalition, lists sex discrimination in employment, education, and access to food and health care; the low status of girls and young women in marriage; and poor (or non-existent) pregnancy, delivery, and post-partum care as remaining unaddressed factors in maternal mortality and morbidity. "Endemic violence against girls and women, especially domestic violence, rape, and sexual coercion, threatens women's reproductive autonomy and right to life. The UN estimates that one in three girls will be raped, beaten, coerced into sex, or otherwise abused in her lifetime," Germain writes.

She points out that to prevent maternal morbidity and death, there needs to be "not only [an] expansion of preventive and clinical care, but also realignment of public health and funding priorities, protection of women's rights, and behavioural changes by individuals, families, and communities."

**B**radshaw's views on the ills of contraceptive non-compliance feed into the view of many in the population control lobby that women must be made to comply with family planning programs: forced to abort or to be sterilised, fined or jailed for having children, denied food, clothing or access to credit for non-compliance, pressured to change religion and abandon their traditional family values. This has led to even more ill-health for women.

To support his views in favour of abortion, Bradshaw wheels out exhibits A and B, sisters Francesca and Lucilia. Here we have the ultimate pro-abortion trump card: young girls who are not only pregnant, but victims of the sexual lust of their father. Of course what these girls have suffered is shocking and an outrage. But what is not questioned is how abortion would have helped them or prevented further violation.

Many pregnant women, already victims of abuse, are forced to seek abortions due to shame and lack of support. Not once do Francesca and Lucilia say they wish their children were not living. But what Francesca does say, revealingly, is this: "they threw me out of the house, my father and mother, and everyone made things difficult for me." Terminating the pregnancy would have been convenient for everyone else—covering up the evidence of the abuse and possibly paving the way for her to be raped again. No one asks—or seems to care—what abortion may have done to her mind and body.

Abortion does nothing to deal with the structural reasons behind poverty

and violence—it just adds to them. Does abortion stop women from being raped, beaten, neglected, genitally mutilated, replaced by more satisfactory wives or concubines? Does it stop them from being malnourished or under-educated? That's why the Church provides life-affirming options for women who are pregnant and without support and why it fights for structural changes and public policies which help women and children.

Nafis Sadik, former director of the UN Population Fund (UNFPA), claimed on the program that Pope John Paul II blamed the irresponsible sexual behaviour of men on women. This is implausible given that it contradicts everything the Pope has ever said and written on the subject of responsible sexual behaviour and mutual love and respect between couples. It is also somewhat difficult to believe, coming as it does from a woman who for years denied there was any coercion in China's population control program and held China up as the family planning model for the world to follow.

A good old church-bashing is hardly complete without tossing in some condoms—next on Bradshaw's list of the Church's deadly sins.

AIDS has, of course, killed more than 20 million people worldwide and now infects 42 million, according to UNAIDS. The global epidemic killed more than three million people in 2003 and an estimated five million acquired HIV in that year.

Many—including Bradshaw—appear to think the disease will diminish in direct proportion to the degree of condom use. But they are wrong.

Dr. Edward C. Green, a senior research scientist at the Harvard School of Public Health and a member of the President's Advisory Committee on HIV/AIDS, recently told the U.S. Medical Institute for Sexual Health: "Twenty years into the pandemic there is no evidence that more condoms leads to less AIDS . . . we are not seeing what we expected: that higher levels of condom availability result in lower HIV prevalence."

A 2003 UNAIDS review of condom effectiveness (Hearst and Chen, 2003) concluded, "There are no definitive examples yet of generalised epidemics that have been turned back by prevention programs based primarily on condom promotion." In fact, as Green, who is also author of *Rethinking AIDS Prevention: Learning from Successes in Developing Countries*, has pointed out, countries with the highest levels of condom availability also have some of the highest HIV prevalence rates in the world.

A 2000 article in *The Lancet* by John Richens *et al.* found that "it is hard to show that condom promotion has had any effect on HIV epidemics . . . but the strength of the evidence to link disease prevalence with condom promotion is unclear. Similar declines in prevalence of disease have been observed on

countries with low condom uptake, such as Uganda . . . a vigorous condom promotion policy could increase rather than decrease unprotected sexual exposure if it has the unintended effect of encouraging a greater overall level of sexual activity.”

The BBC’s Bradshaw presents a Catholic father, husband and AIDS sufferer of six years who has made a decision of great self-sacrifice to protect his wife from infection—he does not have sexual relations with her. “It’s difficult but we have to control now because if you don’t control we know the risk,” he says.

This man doesn’t believe condoms are 100 percent safe. And, like many in his part of the world, he is probably sick to death of attending funerals all the time. But his noble desire to protect his wife is portrayed as the result of “rumour and superstition.” And, naturally, the Church is to blame.

Yet condom manufacturers, the World Health Organisation—and my own Australian Government—recognise that only abstinence offers complete HIV protection, and that while condoms might make sex “safer,” they will never make it “safe.” The makers of Durex condoms say quite clearly that “for complete protection from HIV and other (sexually transmitted infections), the only totally effective measure is sexual abstinence or limiting sexual intercourse to mutually faithful, uninfected partners.” Yet when the Church upholds abstinence as the only way to prevent transmission, it is accused of being inhumane.

A recent Cochrane review of the medical literature found that condoms reduce heterosexual transmission of the HIV virus by 80%. The best case scenario as found in the review was 94.2% effectiveness and the worst case scenario was a disturbing 35.4%. Both the Cochrane review and the Atlanta-based Center for Disease Control (CDC) warn that reduction in HIV transmission through condom use depends on *consistent* use, and they caution that even perfect use cannot give any person lifetime protection against HIV. But you don’t hear that very often from the condom brigade.

Edward Green says that the data on condom effectiveness should help set policy and that people in developing countries should be told about this risk. He told Newstracker that one chance in 10 of condom failure is “not good enough for a fatal disease . . . The way condoms are marketed in Africa and other developing parts of the world is as if they were 100 percent safe. Condoms have brand names like Shield and Protector that gives the impression that they are 100 percent safe.”

Let’s visit Uganda for a moment. This African nation once had the highest rate of HIV in the world, but infection rates have declined from 21 percent

to six percent since 1991—"a remarkable feat," according to UNAIDS in its AIDS Epidemic Update (December 2003). "To date," it reports, "no other country has matched this achievement . . ." It seems the Ugandan Government realised it had to do more than teach primary school kids how to put condoms on bananas. It set about changing sexual behaviour.

In testimony before the African Subcommittee of the U.S. Senate in May of last year, Green explained that the Government of Uganda, led by President Museveni, developed a distinctive approach to AIDS prevention known as ABC: Abstain, Be faithful, or use Condoms if A and B are not practised. The abstinence message for the most part took the form of urging youth to delay having sex until they were older, and preferably married.

Now here's a fascinating confession from Green: "Many of us in the AIDS and public health communities didn't believe that abstinence and faithfulness were realistic goals. It now seems we were wrong." He continues: "We know that prevalence decline and changes in sexual behaviour were most pronounced in youth aged 15-19. These findings took many of us by surprise, since we believed that teenagers are driven by 'raging hormones,' therefore abstinence is an unrealistic or impossible objective."

Green told the subcommittee that according to studies by the World Health Organisation, the proportion of young males aged 15-24 in Uganda reporting premarital sex decreased from 60 percent in 1989 to 23 percent in 1995. For females in Uganda, the decline was from 53 percent to 16 percent.

In a more recent study (also cited by Green to the African subcommittee) on the impact of a school-based AIDS education program in Soroti District, Uganda, baseline and follow-up studies of Primary 7 pupils (age 13-16) showed that as an apparent result of the school AIDS prevention program, self-reported sexual activity among boys dropped from 61 percent for the class of 1994 to 5 percent for the class of 2001, while in girls the change was from 24 percent in 1994 to two percent in 2001.

The prevalence of multiple sexual partners also decreased. An evaluation of one faith-based project, also in Uganda and cited by Green, found that those reporting two or more sexual partners declined from 86 percent to 29 percent for men, and from 75 percent to seven percent for women.

As Green told the Medical Institute for Sexual Health, "having multiple sexual partners drives AIDS epidemics. If people did not have multiple sex partners, epidemics would not develop or, once developed, be sustained."

Abstinence. Mutual monogamy. Fidelity. Christians say it, and they're labelled "missionary terrorists." Others say it and it gets published in important journals.

Empowering women to say no to unwanted sex is another life-saver. The

Ugandan government also took steps to raise the status of women. One question the U.S.-funded Demographic and Health survey put to women was: did they believe they had the power to refuse unwanted sex? Of all African nations, Uganda ranked first.

More women need to be strengthened to resist unwanted sexual advances (the risk for girls of contracting HIV is up to 600% greater than for boys.) A recent report on adolescent sexuality by the UN Population Division reveals sexual intercourse by girls under 15 years of age usually occurs under pressure. A recent survey in Australia by the Crime Research Centre at the University of Western Australia found that 14 percent of girls were coerced into unwanted sex.

French teenager Valerie, 17, is a poignant example of a young woman who wishes she had not given in. Her first sexual experience was at 13 and after four years of deadening sexual encounters (including in McDonald's toilets with a man 10 years older), she now believes that "a girl is a slut—that's all, an object." A participant in the French documentary, "Girls Talk About Sex," she says: "I regret that I didn't say no when I didn't want to do it, that I didn't say no the first time, that I didn't say how I really felt at the time, that I didn't say that it didn't feel good, that I didn't tell the truth." Asked for her definition of love, she responds that she would not be able to answer that question. It is clear she has no experience of what love is.

Green cannot emphasise behaviour enough. "AIDS prevention is largely a behavioural problem that requires a behavioural solution," he told the U.S. Energy and Commerce subcommittee. "I believe that AIDS prevention programs in Africa and the developing world generally have become too focused on medical technology and [STD] drugs and not enough on behaviour. Evidence from Uganda and some other countries show that when faced with a life-threatening danger, people can and will modify their behaviour, once they are given the right information, in the right way."

Unfortunately, however, efforts to modify behaviour are often stymied by a western libertarian view that this is an infringement of sexual freedom. Yet those countries who have remained free from this mindset are the ones now reaping positive results.

In a paper titled "Culture Clash and AIDS Prevention" (2003), Green (who, though labelled a conservative by his opponents, isn't one) says, "in the minds of Western AIDS activists and public health professionals, no one should judge someone else's sexual behaviour. This leads to 'moralising' about behaviour, and which should not have any place in public health. Yet Ugandans who turned around their AIDS epidemic did not know they were supposed to remain value-neutral."

Green also told the U.S. Senate's African subcommittee: "The distinctive Uganda ABC model of the earlier period, the one developed primarily by Ugandans for Ugandans, is the one that seems to have worked best, and is the one that had the most to teach the rest of the world."

But there are many in the rest of the world who don't want to learn. "Condoms, Condoms and More Condoms" is the title of a paper written by Professor Doug Feldman, a critic of the ABC approach. Kevin Osbourne, another ABC critic, has written in AIDSLink: "We should put our global energies behind ensuring that sex—coercively or by will—is safe and that condoms are readily available." That must be of great comfort to school-girl virgins raped by older men, and the child brides who have no say over their fates. Perhaps the latex lovers could come up with a new slogan: "If he's going to rape you make sure he's using a condom." It seems even coerced sex is beyond the judgment of some. As Green comments: "The truth is, for all our enthusiasm about stigma reduction, empowerment of women, poverty reduction, political activism and the like, when it comes down to it, what the donors fund in AIDS prevention is pretty much reduced to condoms."

Another under-resourced area is antiretroviral drugs and related medications, tragically rare for most people in the developing world. As well, only one percent of pregnant women in countries heavily affected by HIV/AIDS have access to services to prevent mother-to-child HIV transmission. Recent research at a Georgia (U.S.) hospital found that if women have received complete prenatal care, HIV testing and AIDS drugs, HIV was never transmitted to their children. As UNAIDS states, it must be ensured that "treatment access is equitable and that it benefits the poor and marginalised sections of societies, especially women."

The story has to be more than about condoms. Even the United Nations Population Fund in its *State of World Population Report: Investing in Adolescents' Health and Rights 2003* concludes: "Promoting condoms as providing 100 per cent protection could inadvertently encourage high-risk behaviour." This is echoed in the view of Vinand M. Nantulya, senior health advisor at the Global Fund to Fight AIDS, Tuberculosis, and Malaria, who says, "If we tell youth that if you use condoms, you will be safe, then we are actually fuelling the epidemic." It's also reinforced by Hearst, who told the Medical Institute for Sexual Health that we are "raising a generation of young people in Africa that believe that condoms will prevent HIV . . . the most recent Meta-analysis came up with 80% . . . but even if it is 90%, over time it's the question of when, not if . . . you don't want to give people a false sense of security and A and B are better in the long term."

MELINDA TANKARD REIST

But in this age of unlimited sexual license and so-called sexual freedom, few want to promote a message that tells adolescents that abstinence is their only real safe choice—a choice that will save their lives and protect their health.

*Sex and the Holy City* promoted the Western enlightenment view that Third Worlders live an “animal existence” and can only be saved by embracing the lifestyles of the bold and beautiful in the West—though without any offer of the West’s wealth and opportunities. In a world torn apart by broken relationships, poverty, disease, suffering and violence, developing countries are offered condescension, abortion and a latex mountain. But the Church takes the position that where injustice occurs it must be redressed and offers a Gospel which it believes will bring life and healing, because it is based on the principle that love should be a protective and not a destructive force.





# A Question that Begs for Moral Illumination

William F. Buckley Jr.

I take this occasion to speak out loud thoughts I don't doubt many of you have had, but perhaps not so many have expressed.

We need, I think, at a dinner at which Catholic Christianity is especially prominent, to inquire into several questions.

I begin by citing a datum you are all familiar with. It is that there is no identified difference between the use of artificial birth control by Catholics and non-Catholics, indeed, by Catholics and non-Christians, if we correctly read the data.

This is what in days gone by would be called a scandal. In a formal sense, this is still what it is, inasmuch as to use birth control of that order flouts the teaching of the Church.

We set out, then, with this premise, namely that there are diminishing differences between Catholics and non-Catholics in respect of religious commandments. A prime example, of course, is the law that commands us to observe the Sabbath, in the case of Catholics, by specific adjurations to attend Mass on Sunday.

Recent statistics regarding church attendance in Europe inform us that weekly attendance in Catholic countries, for instance France and Italy, is in the neighborhood of five percent. We can assume from our own experience of life here, and elsewhere, that those who do not attend church on Sundays, like those who practice birth control, do not stop to confess their sins before engaging a priest to marry their daughters, or to bury their mothers.

The arguments for mechanical aid in the regulation of birth are well known, and all but universally accepted, without any obvious deference to the authority on moral questions nominally exercised by the Church.

Even so, we hang onto the theological arguments as a way of affirming our belief in the sacredness of life. The failure to abide by a law is not, in a discipline removed from any required of democratic reaffirmations, a sufficient reason to invalidate that law.

Yet we remember that Christianity, in the language of St. Thomas, does not ask of us to believe something that cannot be believed *ut in pluribus*, by the majority of the faithful exercising normal powers of reasoning. On the matter of birth control, the disparity between what is taught and what is practiced leaves in suspense the question whether, *ut in pluribus*, those who defy the law are in fact capable of understanding

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that law as explicated to us by the successor to St. Peter.

Putting this anomaly to one side, but keeping it in mind, I ask whether the present company, in particular the gifted editors and contributors to the *Human Life Review*, oughtn't to ventilate another concern, this one having to do not with the beginning of life, but with its ending.

I remember with what dismay, here and there verging into fury, the judgment of Ernest van den Haag was greeted when, in *National Review*, he pleaded the moral authority of a human being, in certain circumstances, to order an ending to his own life.

In making the argument, van den Haag accepted sensible limitations. A plea by the jilted young man to be allowed to follow the example of Romeo on the loss of his own Juliet was not, in the van den Haag code, to expect legal or social acquiescence.

But hearken here to an important point. Van den Haag's departure from convention was in two stages. He did not believe that the state had a sovereign role in denying the right of the individual to make such a decision; and here, Christians and non-Christians might find common ground. We do not expect the state, nor require it, to outlaw every practice we disapprove of. The state's responsibility to protect the unborn issues from its responsibility to protect innocent parties. For many years, as we know, abortion was forbidden by state laws. Public attitudes began to change in the late Fifties, but when *Roe v. Wade* was decided, only one or two states had authorized abortion.

Who would deny that the Christian community would welcome as a great millennial blessing the repeal of *Roe v. Wade*, even if that repeal left individual states free, politically, to authorize the practice, as for instance the State of Connecticut has preemptively done.

The moral argument against abortion would not diminish. Yet most would welcome, as a measure in the right direction from the status quo which guarantees the right to abortion as a federal matter, a devolution of authority to the political mechanisms of the states. The Church is not inattentive, in my understanding, to the matter of moral qualification. Thus, under certain circumstances, lies, even if not authorized as such, are more readily understandable, in the forum of moral thought, when done with extra-personal motivation.

It is simply not arguable that, in the present age, someone who takes his life when, let us say, incapacitated by cancer, is deemed less contumacious than one who does so while in good health.

What I wonder about, and make bold to introduce the question in this unique company, is whether the time has come for the moral arbiters of Christian teaching to take into account developments not anticipated.

Foremost of these, of course, is the unique boost to longevity brought on by science. There is no need to specify here. Everyone in this room knows personally, or knows about, one or more cases that highlight the question.

Such cases are by no means all of them clear cut, the contingent will of the individual not being automatically discernible. A story in the newspapers this week speaks of a woman for several years stricken into physical and mental immobility. Artificially administered sustenance keeps her alive. Her husband wishes, after years of standing by, to activate her death from malnutrition. Her parents argue against that measure.

Karen Ann Quinlan is the textbook case of the dilemma taken to extraordinary lengths. After several years of comatose life, taking counsel with a priest, her parents agreed to disconnect the respirator which had been presumed responsible for her survival.

This was disconnected, but she lived on, lived on for several years. I do not know the proximate cause of her death, but do not doubt that the end was greeted with relief—by everyone.

Pope Pius XII counseled in an important encyclical against the use of what he called “heroic therapy” to prolong life. That was a half-century ago. Can such thought as gave rise to the factor of moral qualification apply today, a fortiori, to life that goes on, unwelcome by everyone, imposing great strains on the medical community, and strains also on family and beloved friends who need to act as though the insensate person were still with them, an active member of the family, though such is not the case? Exposing surviving loved ones to the sundering emotional drama of living with someone as though alive, though for all sensible purposes dead?

This is the question I hope the *Human Life Review* will probe, inviting its superb stable of theologians and journalists to give thought to a question that begs for moral illumination.

Those of us who celebrate the beginning of life, should know to celebrate the ending of it, in appropriate perspectives. It is such perspectives I pray the Christian community will advance, with hard thought given to a major problem in Christian adjustment to lives prolonged by the industry of science and the countenance of God, by many years, but stopping short, as is foreordained, of that infinity which comes to us only after our death, and ought not to be put off by the abuse of God’s blessing for protracted lifetimes.

I have no recommendations to make, desiring only to hope for creative, not merely accommodationist, theological thought on the matter. And to close by reiterating the debt I think we all feel, to Jim McFadden, foremost, and to Henry Hyde as the most prominent legislative champion of our cause, and to Faith and Maria McFadden for persevering in their holy work.

## Bearing Witness

George McKenna

I grew up reading and listening to William F. Buckley Jr., and I was always in awe. As a teenager and young adult, I loved the deft way he sliced and diced his debate opponents, never losing his own cool. Since I was a New Deal Democrat I often disagreed with him, but that didn't matter. His wit, his urbanity, his dead-on accuracy in getting to the heart of an issue not only raised the level of political discussion but made it fun. I was privileged to meet him only once, briefly, in the 1980s when I was chairman of the Political Science Department at City College of New York. I invited him to come to the College and debate the director of Phoenix House, a drug rehabilitation center in New York City, on the topic of drug legalization. He came, *pro bono*, and argued with his usual lucidity and eloquence. The debate was a huge hit with the students, and afterwards I told him how much I appreciated his kindness.

So it was with abundant good feelings that I anticipated Mr. Buckley's speech at the dinner last fall honoring J.P. McFadden, founder of the Human Life Foundation. I had never met Mr. McFadden, though I had great admiration for the extraordinary work he had done for the pro-life cause. Mr. Buckley, of course, had known him as a friend and colleague for many years, so I looked forward to hearing his recollections.

What I heard instead was an argument—presented as a “question I hope the *Human Life Review* will probe”—for withdrawing feeding tubes from patients who are unable to communicate with their doctors and family.

Reflexively, my reaction was, “no, this isn't right.” Later, I had to sort out why it wasn't right. Certainly not because it was wrong to argue it, or because nothing can be said for the argument. There are provocative arguments on a variety of topics which, painful though they are, deserve impartial and unimpassioned discussion. I happen to think that the argument of Richard Herrnstein and Charles Murray in *The Bell Curve* belongs in that category. The question is whether it would be fitting to argue it as a guest speaker at a dinner honoring Martin Luther King. I don't think it would, just as I do not think that it is proper to introduce a pro-death argument—bluntly, that is what Mr. Buckley's argument amounts to—at a dinner honoring the founder of the *Human Life Review*.

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Well, what's done is done, so why bring this up now? Here is why. I may be presumptuous in making this assumption, because I personally know only a few people who were in the audience that night, but my hunch is that Mr. Buckley's argument, like his choice of the occasion for making it, was out of touch with the people to whom it was directed. I'll come back to this point later.

What I want to do first is to try to follow the route of his argument. As soon as I do, however, I find that the road forks off in different directions and sometimes disappears entirely. Starting (I gather) with the assumption that his audience consists largely of Catholics, he reminds them that the Church requires weekly Mass attendance and bans contraception. Then he observes that the majority of Catholics are violating these Church laws. The Catholic Church is not, of course, a democracy, so the fact that its rules are disregarded does not, by itself, invalidate them. "Yet we remember that Christianity, in the language of St. Thomas, does not ask of us to believe something that cannot be believed *ut in pluribus*, by the majority of the faithful exercising normal powers of reasoning." Therefore . . .

Therefore, what? Therefore, Catholics may discard Church directives that are not widely followed? He doesn't say. Instead, without any warning at all, he suddenly gives us a new road to follow. Recalling the furious reaction from readers of the *National Review* to an article by Ernest van den Haag that argued the case for assisted suicide in certain circumstances, he protests that van den Haag was simply suggesting that people ought to be able to decide their own fate without state interference. Even conservative Catholic theologians, he says, don't expect the state to outlaw every practice they consider sinful. Therefore . . .

Therefore, what? Therefore, people should be legally permitted to commit *any* act contrary to traditional Western morality. Or only some? If some, which ones? He doesn't say. Some listeners might have thought they heard echoes of a famous argument made in 1984 by then-New York Governor Mario Cuomo. It went along these lines: "As Catholics, Matilda and I think abortion is gravely immoral. But do we have a right to force our beliefs on people who are not Catholic?" The Cuomo argument has already been decisively refuted (hint: try substituting "rape" for "abortion"), but, in fairness to Mr. Buckley, that doesn't seem to be quite what he means. What he actually seems to say is that the ultimate decision should not be left to individuals but to individual *states*. "Who would deny that the Christian community would welcome as a great millennial blessing the repeal of *Roe v. Wade*, even if that repeal left individual states free, politically, to authorize the practice, as for instance the State of Connecticut has preemptively done."

Now, that is certainly true. If *Roe v. Wade* were repealed, Connecticut and no doubt some other states would still keep abortion—but abortion wouldn't remain in all fifty states. Right now the legal status quo is abortion everywhere, so a "state prerogative" solution, by peeling away many of the states from abortion, would be movement in a pro-life direction. But, when van den Haag was advocating physician-assisted suicide in the pages of Mr. Buckley's journal, the legal status quo was against it. Physician-approved suicide was not legal anywhere in America. In *that* context, his "state prerogative" proposal would not move the ball toward life, but in the opposite direction. It would not be a great millennial blessing but a tragic reversal in the protection of human life. By conflating historical contexts that are exactly opposite, Mr. Buckley has made moral retrogression appear to be moral progress.

But the case we are concerned with here is not physician-assisted suicide. It is not about something one does to oneself (with assistance) but about something one does to another. It is about removing a feeding tube from somebody who is unable to tell you whether she wants that to happen to her. If the tube is removed from her, Terri Schiavo will surely die of hunger and thirst. Her husband, who now lives with another woman and is raising children with her, wants to "activate her death," as Mr. Buckley puts it. Her parents are fighting what appears to be a last-ditch legal battle to keep her from death. Mr. Buckley sides with the husband. He also wants to "activate her death," and he thinks he may have the Vatican on his side, at least in terms of its own principles. He cites Pope Pius XII's encyclical against the use of "heroic" means for keeping people alive, and he thinks that feeding tubes belong in that category.

**I** have to pause for a moment to confess my bewilderment. He began his talk by suggesting that on some major questions most Catholics aren't listening to the Church anymore. Without quite dismissing its authority, he seemed to be saying that the Church is somewhat irrelevant today. Now, all of a sudden, he wants to get the Church on his side! So what *is* his position? Is it that the Church is out of step with the world today, or that the Church is very much in step, perhaps even in the *avant-garde*? Or could it be both: the Church is sometimes out of step and sometimes in step, depending on whether its positions can be made to conform to those of Mr. Buckley? I don't know the answer, but I will assume Mr. Buckley's good faith in associating his position with Pius XII's position on "heroic" means of keeping people alive.

What is "heroic"? The *Catechism of the Catholic Church* refers to "over-zealous" treatment, and I believe Pius XII put it in the context of therapy

made possible by the latest, most sophisticated technology. Today we have respirators, heart-lung machines, dialysis, chemotherapy treatments and other means of keeping people alive which did not exist forty years ago. Do feeding tubes belong in the same category? If I am not mistaken, feeding tubes were used on hunger-striking suffragettes in the early years of the last century. Basically, we are talking about food and water here, substances as old as life on earth. Mr. Buckley says that in this case they are “artificially administered.” Feeding tubes are of course artificial. So are soda straws and baby-bottle nipples, which for some are also necessary to sustain life.

I do not mean to gloss over some very real problems of medical ethics. Sometimes there are no easy answers. In individual cases involving patients on life support, a number of factors must be taken into account. One of them concerns the wishes of the patient. Without necessarily implementing them, we respect them; we listen, because we respect the human person. What of persons who lie in hospital beds, without the power to communicate, and have left no clear prior indication of their wishes? It would not be unreasonable to assume that someone who is at the natural end of a long life, or in the last stages of an incurable illness, would prefer not to be put on a feeding tube. If that assumption is correct, what is to be done? I have no formulaic answers. Tough calls sometimes have to be made in individual cases, though in Western morality a special weight has always been assigned to the intrinsic value of human life. Call it pro-life affirmative action.

Terri Schiavo’s case is not a tough call. She is a young woman, not someone living at the far end of life, she is not at the last stages of an incurable illness, and she is not being considered for a feeding tube, she *is* on a feeding tube, the removal of which will certainly “activate her death,” in Mr. Buckley’s phrasing. He does not make it quite clear, but he seems to be referring to Terri Schiavo when he denies that there could be any reason for prolonging a life “unwelcome by everyone, imposing great strains on the medical community, and strains also on family and beloved friends who need to act as though the insensate person were still with them, and an active member of the family, though such is not the case.” Hardly any of these descriptions fit Terri Schiavo. She does not look “insensate” to me, nor, apparently, to a board-certified neurologist who had seen her and reported a “definite cognizant function.” She is beloved by her parents and siblings, who are desperately fighting to keep her alive. As for her being an “active member of the family,” that seems to be raising the bar pretty high, but even here, in her own way, she seems to have moved her family to take action on her behalf. If I remember my metaphysics, a causal agent is by definition “active.”

I have been speaking of Terri Schiavo in the present tense, yet by the time

this piece is published she may no longer be alive. One or two more decisions by the Florida courts could wipe out the protections accorded her by the legislature and governor, and her death will be activated. Let me, then, move from present to future-conditional.

If she loses in the courts and her feeding tube is removed, it will take about ten days for her to die. (Sometimes people can go two weeks, but her body has already been weakened by the previous removal.) During this time she will feel the pain of hunger and thirst, for Terri is not a patient in the last stages of life who has refused food and drink for want of any craving for them. She is mentally impaired, but otherwise she is like us. (Try going *one* day without food and drink and see how you feel.) Author Wesley Smith has interviewed neurologists about what happens to patients when their feeding tubes are removed, and from what he wrote we can expect the following to happen to Terri: Her skin will become extremely cold, mottled, and then crack; her tongue and lips will also crack. She will likely have nosebleeds because of the drying of the mucus membranes, and vomit because of the drying of the stomach lining. At some point she may go into seizures. It will be an agonizing death, and I doubt that it will be “greeted with relief,” which Mr. Buckley thinks was the reaction by “everyone” to the death of Karen Ann Quinlan. If death by starvation and dehydration comes to Terri Schiavo, and the full story is told, it will more likely sicken everyone.

**T**his brings me back to my original contention—or, to be more modest, hunch—which was that Mr. Buckley may not be quite in touch with his audience. Beginning with the assumption that he was speaking to a Catholic audience, he cited certain Church doctrines and sought to draw some conclusions from them. Although I personally know people in that audience who were not Catholic, I won’t quibble with that assumption; probably the vast majority of people there (like the readers of this journal) were indeed Catholic. Where I think the mistake lies is in his second assumption: that they derive their aversion to killing innocent people from their Catholic faith. My assumption is that he is making this assumption, because his argument works largely within the framework of Church doctrine. It has little to say, for example, to an atheist like *Village Voice* columnist Nat Hentoff, who also opposes abortion, euthanasia, and the removal of Terri Schiavo’s feeding tube. Nat Hentoff doesn’t care at all about weekly Mass attendance or *ut in pluribus*. What bothers him is the taking of innocent life.

Here is a thought experiment. Suppose, at some point during the dinner honoring Jim McFadden, all the Catholics in attendance were suddenly to lose their faith. All their Catholic beliefs, from the intercession of saints to



the Real Presence, disappeared in a flash. Would that in any way change their views on abortion, euthanasia, or deliberately causing the death of a person by dehydration? I don't think so. Catholicism reinforces the pro-life position, puts it into a coherent faith context, but it is not the source of it. What is the source? Here we can turn to St. Paul—not for his theology, for we have to stay away from that right now, but for an anthropological insight he provides in Romans 2:14: “For the Gentiles, which have not the law, do by nature the things contained in the law, these, having not the law, are a law unto themselves. Which show the work of *the law written in their hearts*, their conscience also bearing witness. . . .” (Emphasis mine.) Even if everyone in that room on the night of October 17, 2003 were suddenly to lose the laws handed down to them by Judaism and Christianity, “the law written in their hearts” would still remain. That law says: It is wrong to kill innocent people.

I gave as an example the columnist Nat Hentoff, an atheist who heeds no theological system but only the law written in his heart. Let me cite another person, now dead for many years, who did the same. Mr. Buckley and J.P. McFadden knew him very well, because he served for a time as columnist and editor at the *National Review*. His name was Whittaker Chambers. He was a figure of great controversy in the late 1940s because he exposed Alger Hiss, a former State Department official, as a long-time Communist spy. Chambers knew about Hiss's secret Communist activities, because he had participated in the same activities during the 1930s; he had received stolen State Department documents from Hiss and passed photocopies of them along to Moscow.

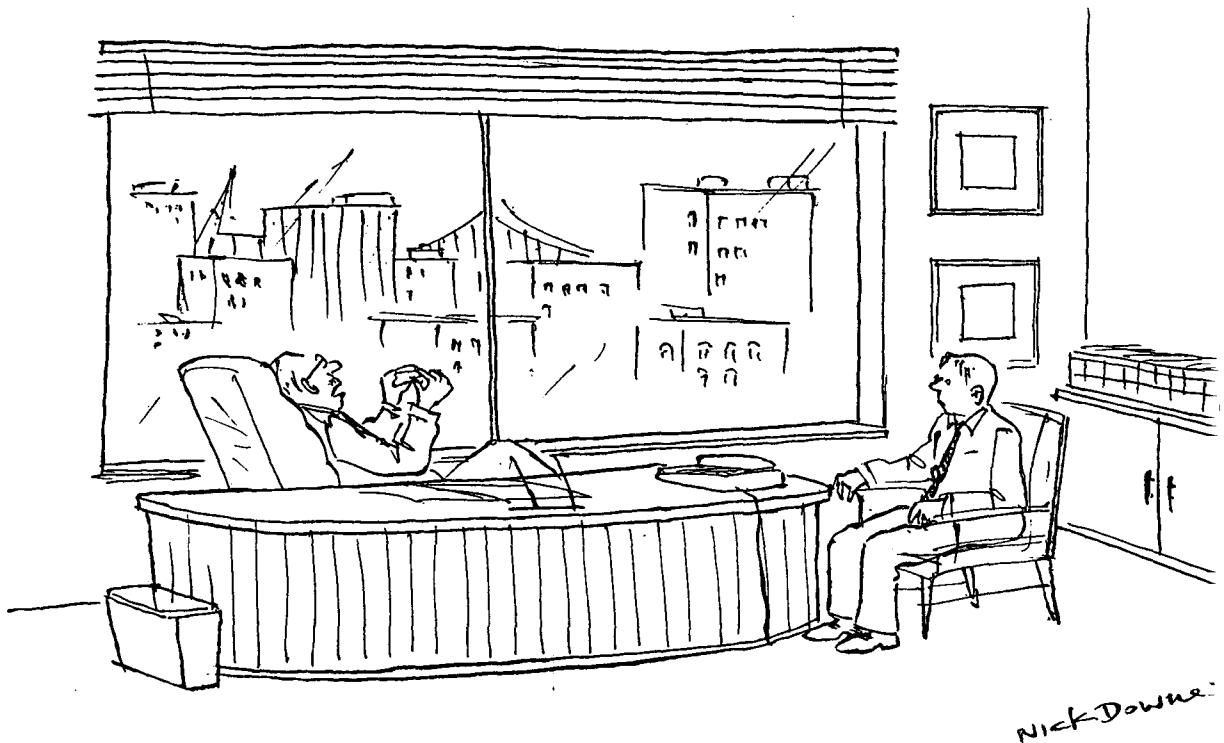
Chambers came from a nominally Protestant home, but he lost whatever scraps of religion he had during college, and of course was a staunch atheist during his thirteen years as a Communist. (He became a Quaker some time after he left the party in 1938.) In 1952 he published *Witness*, a memoir of his Communist years. In it he recalls that in the mid-1930s his wife (who also held no religious belief) told him that she thought she was pregnant. Since this was one of the most intense periods in his career as a Soviet agent, they planned an abortion. His wife went to a doctor to verify her pregnancy, and when she returned, he asked what the doctor said. “She said that I was in good physical shape to have a baby,” his wife replied. Then there was silence. Finally, it dawned on him: he asked if she wanted to have the child.

My wife ran over to me, took my hands, and burst into tears. “Dear heart,” she said in a pleading voice, “we couldn't do that awful thing to a little baby, not to a little baby, dear heart.” A wild joy swept me. Reason, the agony of my family, the Communist Party and its theories, the wars and revolutions of the 20th century, crumbled at the touch of the child.

GEORGE MCKENNA

So it happened that Whittaker and Esther Chambers, having no religious law at the time, joyously went ahead to bring their first child into the world. Their consciences bore them witness.

Mr. Buckley, I fear, has misjudged his audience and readers because he does not speak to what unites them. It is not religious doctrine, precious as that doctrine is to most of them. It is a law written in their hearts telling them that we may not kill people just because their birth will be inconvenient or their death will be greeted with relief. It is *that* law which brought them all out to honor the memory of J.P. McFadden, and it is what motivated Mr. McFadden to sacrifice so much for the journal he founded. It is a very compelling law and, however complicated its implementation may be in particular cases, a very clear law; it can be obscured only by lies and sophistries.



*"I think I'll give Stevens the axe . . . Just thinking out loud, Stevens."*

## Whose Lives Are Worth Continuing?

Nat Hentoff

On October 17, at the commemoration of the fifth anniversary of the death of J.P. McFadden, William Buckley Jr. challenged the *Human Life Review*—and presumably its readers as well as its editors—to consider whether the lives of “insensate persons” should be sustained by “heroic therapy” with resultant “great strains on doctors, family, and friends.”

While he conceded that not all such cases are “clear cut,” the thrust of his concern, in view of “the unique boost to longevity brought on by science,” was that we must confront the real possibility that certain lives are no longer worth continuing.

He mentioned “a woman for several years stricken into physical and mental immobility. Artificially administered sustenance keeps her alive. Her husband wishes, after years of standing by, to activate her death from malnutrition. Her parents argue against that measure.”

The woman, still alive as I write—despite the persistent, ardent attempts by her husband, Michael Schiavo, to have her feeding tube removed, is Terri Schiavo. Mr. Buckley—like the American Civil Liberties Union, which is aggressively supporting the husband’s wishes—clearly has not investigated the facts of the case, and that underlines how far from “clear cut” this and many other such cases are.

Terri Schiavo is not brain dead, is not in a comatose state, is not terminal, and is not connected to a respirator. If her feeding tube is removed, she will starve to death. Her husband insists that he is honoring her wishes before she fell ill—a story contradicted by a close friend who heard Terri Schiavo express exactly the opposite desire. Her husband says she did not want to be kept alive by “artificial means.” If she did say that, did she mean food and water as “artificial means?”

Contrary to reports by the press, she is not in a “persistent vegetative state”; and even if she were, “persistent” is not synonymous with “permanent,” as has been shown by recoveries of patients diagnosed with that condition.

Her “devoted” husband has been living with another woman for years, and with her, he has a child, with another on the way. He has spent a considerable amount of the \$750,000 awarded in a malpractice suit about the care

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Nat Hentoff, a columnist for the *Village Voice*, has authored several books, including *The War on the Bill of Rights* and *the Gathering Resistance* (Seven Stories Press), and *Speaking Freely* (Knopf).

that led to Terri's condition on lawyers relentlessly trying to get her feeding tube removed. Michael Schiavo once succeeded in accomplishing that. Her life was saved by Florida governor Jeb Bush and the Florida legislature by a law that kept her alive but is strenuously being contested on constitutional grounds by the ACLU and Michael Schiavo.

A *New York Times* editorial called for Terri Schiavo to go gently into the good night because—as Mr. Buckley appears to suggest—“true respect for life includes recognizing . . . when it ceases to be meaningful.”

But, as Max Lapertosa, staff counsel for the disability rights organization, Access Living in Chicago, wrote to the *Times*: “Many would lump into this category [of meaningless lives] people with severe autism, multiple sclerosis or cerebral palsy who, like Mrs. Schiavo, are nonverbal and are often described as being ‘in their own world.’”

Mr. Buckley may greatly underestimate how far from “clear cut” these so-called “end of life” situations actually are.

**I**n the Schiavo case, a disability group I have known and respected for years—Not Dead Yet—reminds us: “People have the right to refuse unwanted treatment, and suicide is not illegal. What we oppose is a public policy that singles out individuals for legalized killing [or “mercy” killing] based on their health status . . . This denies us equal protection of the laws.”

The people Mr. Buckley spoke to on October 17 know—as does Mr. Buckley—how dangerously the respect for life has been eroded by proponents of abortion, assisted suicide, and quiet as it's kept, a growing number of advocates of eugenics and indeed euthanasia. Professor Peter Singer—a subject of a number of *Human Life Review* articles—is far from alone.

And, as Wesley Smith has documented in these pages, and elsewhere, the increasing authority and power of bioethicists and hospital “ethics” committees have created a lethal mindset that, to give one example among many, has led to this result:

The ethics committee of the University of Pennsylvania Hospital approved, in 2002, guidelines which stated that “intensive care would not be routinely given to patients in a persistent vegetative or minimally conscious state. Only patients who had explicitly requested such care would get it.”

Terri Schiavo did not have a signed advance directive as to her wishes if a time came when she could not speak for herself. We have only the testimony of her ethically challenged husband as to what those wishes were.

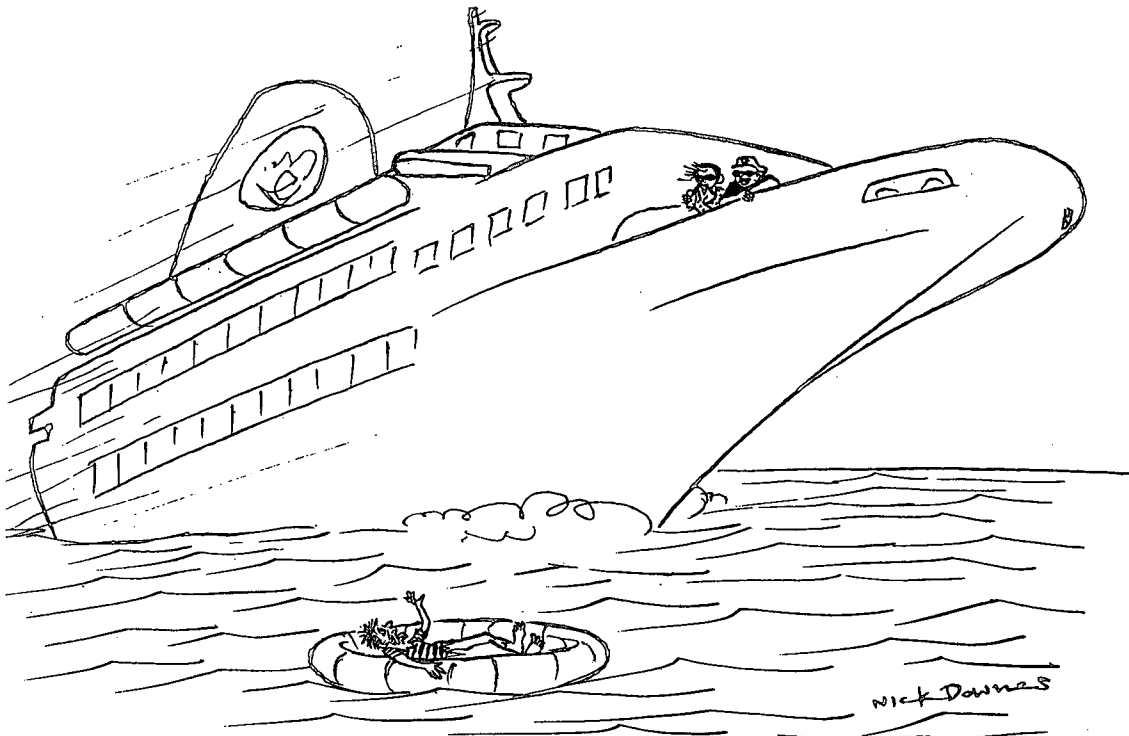
For years, I have consulted on these matters with Nancy Valko, who not only writes extensively and gives workshops on medical ethics, but actually also works full-time (she has great energy) in the intensive care unit of a

county hospital in St. Louis. To recall the title of a former television program created by Mr. Buckley—a program I greatly miss—Nancy Valko speaks from the firing line:

“Just a generation ago, doctors and nurses were ethically prohibited from hastening or causing death. Family dispute and ethically gray situations occurred, but certain actions such as withdrawing medically assisted food and water from a severely brain-damaged but non-dying person were considered illegitimate no matter who was making the decision.

“But,” Nancy Valko reminds us, and Mr. Buckley, “with the rise of the modern bioethics movement, life is no longer assumed to have the intrinsic value it once did, and ‘quality of life’ has become the overriding consideration. Over time, the ethical question, ‘what is right?’ became ‘who decides?’—which now has devolved into ‘what is legally allowed?’”

I, like Mr. Buckley, am pro-life. But, as the late Cardinal Joseph Bernardin illuminated in his “seamless garment” definition of that commitment, being pro-life encompasses more than the killing fields of abortion.



*“What I’d give to be able to just drift like that.”*

## For the Record

Rita L. Marker

In his October 17, 2003 remarks at a dinner held in honor of the *Human Life Review*, William F. Buckley invited those in attendance to “ventilate” about life’s ending. Certainly, it is important to call for discussion about vital issues of the day.

However, he didn’t stop while he was ahead. He went on to discuss facts that he apparently believed were facts associated with such a discussion and then, in essence called for debate with an eye to changing public policy. His remarks didn’t raise eyebrows. They caused jaws to drop. For two reasons.

First, many people (myself included) have always respected Buckley’s intellect. It was, therefore, disappointing that his comments were filled with misrepresentations and inaccuracies. Second, although Buckley may not be an assisted-suicide advocate, he certainly did a good imitation of one.

Buckley claimed to “make bold to introduce” the question about whether it is time to take into account “developments not anticipated.” In so doing, he discussed the case of Karen Ann Quinlan, the words of Pope Pius XII, and the current case of Terri Schiavo.

### Karen Ann Quinlan

The *Quinlan* case,<sup>1</sup> decided in 1976, brought legal clarification to the fact that patients and their decision-makers, not doctors, can request that ventilators be removed. Another outcome of the case was that it highlighted the fact that removal of a ventilator does not always cause death. Karen Ann Quinlan lived for another ten years after her ventilator was removed, eventually dying from meningitis.

In his comments about *Quinlan*, Buckley said her death was, no doubt, greeted with relief. He was acknowledging the obvious. Death often comes as a friend. Was Buckley, however, implying—as do many assisted-suicide advocates—that anyone who opposes euthanasia or assisted suicide wants every patient hooked up to everything but the toaster and the blender until the machines break down?

### Pope Pius XII

According to Buckley, “Pope Pius XII counseled in an important encyclical against the use of what he called ‘heroic therapy’ to prolong life.” It is

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Rita L. Marker, an attorney, is executive director of the International Task Force on Euthanasia and Assisted Suicide.

likely that Buckley was referring to “The Prolongation of Life,” an oft-cited November 24, 1957 address. Delivered during an audience granted to delegates to an International Congress of Anesthesiologists, it focused on concerns about the use of a ventilator.<sup>2</sup> The anesthesiologists had asked if they were morally compelled to continue ventilator support, even if they considered its use completely hopeless and even if the family asked that it be removed.<sup>3</sup>

The Pope replied that, under such circumstances, doctors were not compelled to maintain use of a ventilator.

While this address has been commonly used to explain Catholic teaching regarding “ordinary” and “extraordinary” treatment, Buckley’s depiction of it is skewed. He implied that the Pope had *counseled against* the use of “heroic measures.” Not so. The Pope responded to the anesthesiologists’ questions by saying that people are *not morally required* to make use of extraordinary interventions. Saying one *need not* do something is far different than saying one *should not* do it.

Buckley’s remarks drew attention to Catholic teaching about end-of-life issues. An overview of that teaching can be found in the short, but excellent, article, “Judeo-Christian Teaching on Euthanasia: Definitions, Distinctions and Decisions” by Msgr. William B. Smith.<sup>4</sup>

#### The Schiavo case

Buckley referred to “a story in the newspapers this week” about a “woman for several years stricken into physical and mental immobility.” That woman is Terri Schiavo whose husband, Michael, has sought and continues to seek to have all of her food and fluids withheld.<sup>5</sup>

Ironically, two days before the dinner, Terri’s feeding tube was removed. At the time we were dining, Terri’s distraught parents were keeping vigil *outside* the facility where Terri is a patient. Her husband had barred them and her priest from her bedside. Several days later, after action by the Florida legislature, Terri’s feeding tube was reinserted.<sup>6</sup>

Buckley depicted the situation surrounding Terri as one in which “her husband wishes, after years of standing by, to activate her death from malnutrition.”

This case is not about “malnutrition” which means insufficient or poor nutrition. (One can be malnourished while gorging daily on non-nutritious food.) Michael Schiavo is seeking to dehydrate his wife to death. If he prevails, Terri will be denied any liquid, including any she could take by mouth. This will cause her death within 5 to 21 days. She would experience the agony of thirst, followed by a gruesome death by dehydration.

And what of Michael Schiavo's "years of standing by," as Buckley called them?

During the very time he was asking a court to award millions of dollars for Terri's lifetime care, and in the years since then, he was hardly "standing by."

In a 1993 deposition (just months *after* the court awarded more than a million dollars in the malpractice case), Michael admitted to being in intimate relationships with two women. One had lasted for eight months and the other, which was ongoing, had begun three months earlier.<sup>7</sup> He and the woman with whom he is now living have two children. Obviously, Michael has been doing a lot more than just "standing by."

Another admission during that 1993 deposition is particularly telling. Asked what he had done with Terri's jewelry, Michael said "I think I took her engagement ring and her—what do they call it—diamond wedding band and made a ring for myself."<sup>8</sup> What a guy!

As a husband, he crassly dishonored his vows to his disabled wife. As a court-appointed guardian, he not only stole his ward's property, he also denied her the care and rehabilitation therapy she needed.

#### **Who's blaming the victim?**

Buckley did not stop with misrepresentations and errors regarding medical treatment. He set up a straw man to call for acceptance of suicide for those who are incapacitated. And he presented the views of the late psychoanalyst, Ernest van den Haag, as reasonable and laudable.

Buckley said, "It is simply not arguable that, in the present age, someone who takes his life when, let us say incapacitated by cancer, is deemed less contemptuous than one who does so while in good health."

So who's arguing? I know of no one who is seeking to place blame on suicide victims—incapacitated or healthy. As we would all do well to remember, it is impossible to read the hearts of others. The debate over assisted suicide is not about reading hearts. And it is not, and should not be, about blaming the victims. It is about whether we, as a society, will continue to view suicide as a tragedy, not a choice to be assisted by the medical profession. Assisted suicide does not give additional rights to vulnerable people. It gives power to those who hold medical degrees. It is squarely centered on whether the crime of assisted suicide should be transformed into a medical treatment.

#### **The Voice of Reason?**

Apparently, as evidence that those who oppose assisted suicide and euthanasia are unwilling to consider the views of others, Buckley described the dismay "verging into fury" with which an article by Ernest van den Haag



was greeted.

According to Buckley, van den Haag “pleaded the moral authority of a human being, in certain circumstances, to order an ending to his own life.” He explained that, “In making the argument, van den Haag accepted sensible limitations.”

Although Buckley characterized van den Haag’s arguments as restrained and sensible, they could more aptly be depicted as advocacy for assisted-suicide-on-demand.

In his 1995 article, appropriately titled, “Make Mine Hemlock,”<sup>9</sup> van den Haag lambasted physicians who will not provide the “proper combination and quantities of drugs needed”<sup>10</sup> to suicidal patients, saying such doctors “impose their own socially supported moral beliefs on patients who do not share them, but cannot act unaided.”<sup>11</sup> He followed this condemnation with praise for none other than Jack Kevorkian. “Dr. Jack Kevorkian is a rare and courageous exception.”<sup>12</sup>

His adulation of Kevorkian was tempered by his claim that Kevorkian had “helped only patients who were incurable and, in most cases, had reached a terminal stage.”<sup>13</sup> Van den Haag contended that physicians should be willing to assist the suicide of *any* competent person. “The physician’s task is to inform the patient of his prognosis, perhaps to advise him, and above all, to help him carry out his decision,”<sup>14</sup> he wrote. Apparently, the physician’s mandate to “help” includes assisting a patient who decides to take ninety barbiturate capsules, chased with a few swigs of Scotch—an assisted-suicide method of choice in Oregon.

Van den Haag noted that the refusal of physicians to assist in suicide was particularly unfair to suicidal people with disabilities since they are unable to kill themselves as easily as able-bodied individuals.<sup>15</sup>

Lest anyone point to the specter of Nazi-like practices, van den Haag assured his readers that those practices “were imposed on physicians and hospitals by political directives which did not evolve from any prior authority given physicians to assist in suicide.”<sup>16</sup>

Like Buckley’s, van den Haag’s pontification is misleading, at best. In fact, the Nazi euthanasia program grew out of euthanasia advocacy spearheaded by members of the German psychiatric and legal professions who argued that patients who request “death assistance” should, under carefully controlled conditions, be able to obtain the help of physicians in having their lives terminated.<sup>17</sup> The Nazis expanded upon that advocacy, taking it to a genocidal level. And, even after those programs were underway, physicians were not “ordered” to carry out euthanasia. Rather, they were “empowered” to do so.<sup>18</sup>

As for van den Haag’s “sensible limitations”—as Buckley called them—

he was certain that psychiatrists, “having discarded prejudicial notions”<sup>19</sup> against assisted suicide, would be able to determine whether a person’s “mental processes are realistic and logical to the normal degree.”<sup>20</sup> Once that is determined, “The patient’s decision should be accepted.”<sup>21</sup>

The bottom line? The person whom Buckley held up for admiration advocated assisted-suicide-on-demand for any adult deemed competent by enlightened psychiatrists—those who had “discarded prejudicial notions.”

Buckley began his dinner remarks by stating, “I take this occasion to speak out loud thoughts I don’t doubt many of you have had, but perhaps not so many have expressed.” I would like to end my comments about his remarks by asking a question that, perhaps, many of his listeners had, but did not express: What gave William F. Buckley the right to assume that his listeners were as misinformed as he?

#### NOTES

1. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied sub nom, *Garger v. New Jersey*, 429 U.S. 922 (1976), overruled in part, *In re Conroy*, 98 N.J. 321, 486 A. 2d 1209 (1985).
2. “The Prolongation of Life: An Address of Pope Pius XII to an International Congress of Anesthesiologists,” *The Pope Speaks*, Vol. 4, No. 4 (Spring 1958), pp. 393-398. The Address was first reported in *Osservatore Romano*, Nov. 25-26, 1957. It responded to three questions submitted to the Pope by Dr. Bruno Haid, chief of the anesthesia section of the surgery clinic of the University of Innsbruck. It was delivered during an audience granted to delegates to an International Congress of Anesthesiologists, meeting at Rome’s Mendel Institute.
3. It should be noted that many of the physicians at the International Congress were from European countries. Even today, physicians outside the United States have great authority to make decisions for their patients. Fortunately, American practices are different. Every state permits competent patients to request that medical treatment be withheld or withdrawn. In addition, every state permits individuals to name someone else who can make medical decisions for them if they ever become unable to do so for themselves.
4. Msgr. William B. Smith, S.T.D., “Judeo-Christian Teaching on Euthanasia: Definitions, Distinctions and Decisions,” *Linacre Quarterly* (February 1987), pp. 27-42. The article also appeared in the *New York Medical Quarterly* (1986) pp. 181-190.
5. The controversy surrounding Terri Schiavo has been, and will continue to be, discussed in this publication. It is interesting to note that Buckley referred to her case as part of his plea that it was time to “take into account developments not anticipated.” Terri is receiving food and fluids by means of tube. Presumably, Buckley views tube feeding as such a development. However, tube feeding has been common for more than a century as two articles, published in 1896 indicate (McMurtry, “Modern Gastrostomy for Stricture of the Esophagus, with Report of a Case,” and Coomes, “Gastrostomy, with Report of a Case,” *Transactions of the Kentucky Medical Society* (1896).) See also, “Questions and Answers about ‘Artificial Feeding,’” International Task Force on Euthanasia and Assisted Suicide (2001). (<http://www.internationaltaskforce.org/fctaf.htm>)
6. Florida HB 35-E, called “Terri’s Law,” passed on Oct. 21, 2003. It adds protection for vulnerable people who could be subjected to dehydration death ordered by a court-appointed guardian. It only applies to individuals who do not have an advance directive (living will or durable power of attorney for health care). Even in the absence of an advance directive, a court-appointed guardian could still remove food and fluids from a ward unless a family member objects to this means of death. As this is being written, Michael Schiavo’s challenge to the law’s constitutionality is ongoing.
7. *In Re: The Guardianship of Theresa Marie Schiavo, Incompetent*, In the Circuit Court of the

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Sixth Judicial Circuit of the State of Florida, In and For Pinellas County, Case No. 90-2808-GD, November 19, 1993, Deposition of Michael Schiavo, pp. 3-4, 6. Deposition on file with author.

8. Ibid, p. 80.
9. Ernest van den Haag, "Make Mine Hemlock," *National Review* (June 12, 1995), pp. 60-62.
10. Ibid., p. 60.
11. Ibid.
12. Ibid.
13. Ibid. Actually, van den Haag was wrong about that. Kevorkian's "help" most often extended to non-terminally ill victims, some of whom, on autopsy, were shown to have no diagnosable.
14. Ibid.
15. Van den Haag's emphasis on assisting disabled persons to commit suicide was indicative of a (perhaps unintended) bias against people with disabilities. For a thorough discussion of that bias and its ramifications see: Eric A. Johnson, "Assisted Suicide, Liberal Individualism, and Visceral Jurisprudence: A Reply to Professor Chemerinsky," *20 Alaska L. Rev.* 321 (2003). Disability rights activists have been cognizant of this subtle bigotry and they have effectively mobilized to oppose attempts to legalize assisted suicide. See: Wesley J. Smith, "Disabling Assisted Suicide," *National Review Online*, January 19, 2004 (<http://www.nationalreview.com/comment/smith200401190806.asp>), last accessed 1/29/04.
16. Supra, note 8, p. 62.
17. R. Lifton, *The Nazi Doctors: Medical Killing and the Psychology of Genocide* (1986), p. 47.
18. R. Proctor, *Racial Hygiene: Medicine under the Nazis* (1988), p. 193.
19. Supra, note 8, p. 62.
20. Ibid.
21. Ibid.

# Killing or Letting Die

Francis Canavan, S.J.

As a preliminary remark, let me say that the line between killing and letting die is not always obvious. More importantly, it is not always susceptible to neat, clear-cut, yes-or-no answers. But we live in an age in which multitudes want such answers: the needle on their gauge always stands at zero or 180 degrees, because there is no demonstrable reason why it should stop at any of the other 179 degrees in between. I don't mean that there is a popular clamor for moral rigidity, but rather that there is a popular tendency to assume that if any exceptions to a moral norm are admitted, all exceptions can be admitted.

Mr. Buckley does not assert that, of course, but he cites St. Thomas Aquinas as holding that Christianity "does not ask of us to believe something that cannot be believed *ut in pluribus*, by the majority of the faithful exercising normal powers of reasoning." But I don't think that when Aquinas used that phrase, he referred to the number of persons who could understand and accept a moral norm. Rather, he referred to the distinction between moral norms that oblige *semper et ubique*, everywhere and always, and norms that admit of exceptions in certain cases. He certainly held that the basic norms of morality were binding everywhere and always. Secondary norms could be considered binding *ut in pluribus*, in most cases, but not in all.

Many of the norms concerning the care of the dying are of this secondary nature. In Catholic teaching there are general norms, well known and widely discussed in theological circles, but when it comes to their application in particular cases, disagreement is possible because a number of variable factors are involved in these cases. It is then necessary to make a decision one way or another, but that requires practical judgment (by which I do not mean utilitarian judgment).

I am not a moral theologian (though I did take courses in moral theology), nor have I widely and thoroughly studied the subject before us. For the present discussion, I shall rely on a set of short documents written several years ago by three women, all of them identified as writing for the Department of Health and Hospitals of the Archdiocese of New York. Their topics are: "Nutrition and Hydration," by Mary Jo Mitchell; "What Everyone Should Know About Do Not Resuscitate Orders," by Lucia Migliaccio; and "The Duty to Protect Life: Ordinary and Extraordinary Means," by Diane Hearn.

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It is safe to assume that what they wrote must have been reviewed and approved of at higher levels in the archdiocese. They are not therefore the last and only word on the subject, but they foreshadow the norms approved by the United States Conference of Catholic Bishops on June 13, 2001, under the title “Ethical and Religious Directives for Catholic Health Care Services” (4th ed.).

The quotations that follow are from these archdiocesan documents. Their basic premise is that “life is a gift which we hold in trust, and not a possession over which we have complete control.” Consequently, “we are obliged to seek ways to enhance and prolong human life and to use all *ordinary* means toward this end.” In recent years “the most controversial and emotional” issues in this area concern “the termination of artificial nutrition and hydration.”

Aristotle says somewhere in his writings that the ability to think consists largely in the ability to make distinctions. In another place he says that most people are not very good at making distinctions. One basic distinction is between the terminally-ill (dying) patient and the patient who is seriously but not terminally ill (not dying). “It is widely acknowledged that excessive medical treatment can be withdrawn if it is non-beneficial or [is] burdensome to the terminal patient. However, the question of whether artificially induced nutrition and hydration [food and fluids received through tubes inserted into the body] is a medical procedure or simply a way of addressing basic human needs, has never been clearly defined.” The question, therefore, is both disputed and important.

The writer quoted above concludes: “If such a procedure can prolong or support life without being a burden to the patient, then this procedure is deemed *ordinary*. When judging the burden, the emphasis must be on the patient himself, and not on whether a burden is placed on the community, third-party payers, or family.” But an “intensive review” of each individual case must be made before the procedure is judged ordinary or extraordinary.

The advances in medical technology and procedures have been extensive and dramatic in my lifetime, especially in recent decades. Another writer in this set of documents states the question raised by these advances in these terms: “Does the very fact that technology and science have made a multitude of choices possible require that any and all means be employed in the treatment of illness?” She replies:

The Church teaches that one is always morally bound (obligated) to take *ordinary means to preserve life*. By “ordinary” is meant those treatments which offer *reasonable* hope of benefit to the patient, and which do not entail for the patient a grave burden (psychological, physical, emotional, or, in some instances, even financial) or

suffering greater than the illness itself presents. Included in ordinary means are those very basic and obligatory means the reverence for life itself demands, namely; food, water, personal hygiene, comfort, and support. In addition, those treatments, procedures, and courses of medication commonly used with reasonable success usually fall within the framework of ordinary . . . .

Then she adds: "The Church never requires that extraordinary means be employed." But the means she describes as ordinary require the careful use of practical judgment in which several factors must be weighed. To jump to the conclusion that therefore the goal of reducing pain outweighs all other considerations is not an exercise of practical judgment.

The paper on cardiopulmonary [heart or lung failure] resuscitation (CPR) and "do not resuscitate" orders (DNR) under the laws of the State of New York concludes with the remark, "The church does not have a problem with DNR orders so long as they are used in the appropriate way to avoid causing further infirmity resulting from CPR and/or to avoid prolonging inevitable death."

**I** am aware that criticism of what I have recited above is possible and may well be correct on certain points. I only wanted to show that much thought has been given within the Catholic Church by both clergy and laity, and by the hierarchy, and that certain issues are open to further discussion.

As for myself, I agree with the Book of Ecclesiastes that there is a time to be born and a time to die. When my time comes (whether as a result of incurable disease or simply old age), I hope that they will let me die in peace. I do not want them to keep my heart beating and my lungs breathing, without solid hope of recovery, after my eyesight, my hearing, and my mind have vanished, simply because they have the technology to do it.

Having said that, let me add that I regard the issue as of minor importance in the "culture of death" of which Pope John Paul II has spoken. It is a culture that does not regard death as good in itself. But it is a this-worldly, secularist culture in which pain of any sort is the greatest of evils, all goods are reducible to pleasure, and death is the universal escape hatch. This attitude justifies doctor-assisted suicide, whether chosen by the patient or, if he is unconscious, by the doctor. It also justifies the generation of new human lives in the laboratory for purposes of experiments that may find cures for diseases, but will destroy the newly-generated human lives.

We are living through the dechristianisation of Western culture, the obverse side of which is its recrudescence of pagan morality. One of my sisters told me that on an airline trip she took from Hong Kong to Bangkok, the Chinese gentleman sitting next to her asked, "Why do you Westerners attach

so much importance to human life?" "I was finally reduced," she told me, to saying, "But everyone knows." And everyone would know in a culture built upon the religions of the Bible, which teaches that God created man in His own image and likeness—but not in a pagan culture. That sad reality makes preserving our belief in the sanctity of human life more important than determining how far we must go before letting it go.



*"Frankly, I'm more of an agnostic."*

# Our Sister Terri

*Mary Jane Owen*

**“W**hen will the bitch die?” is the question asked by the husband as reported in a sworn statement of a nurse who cared for Terri Schindler Schiavo in the early days of her hospitalization. She has tenaciously clung to a life others have judged as worthless in spite of orders by her husband and the courts that she be killed by dehydration and starvation.

Many of us who have been judged as having lives of marginal value are frightened of the prejudice highlighted by Terri’s plight. Neither the political Left nor Right seems to “get it” that negative stereotypes motivate perceptions of Terri’s life. Bioethicists and many medical and legal professionals fail to comprehend the discrimination they are fostering. And the general public is bombarded by reports from a biased media sympathetic to the utilitarian script of the culture of death advocates.

Christians might be expected to have a less simplistic view of suffering since we base our hope for salvation on a disabled crucified Christ. Have we Catholics noticed the role of pain in the lives of our saints or the numbers of them who lived with disabling conditions?

Why did the view that some “flawed” lives are useless or that people with disabilities should be valued only if they can think abstractly become so popular? And when, in heaven’s name, did a simple feeding tube turn into a burdensome hi-tech medical intervention?

Recently the National Catholic Partnership on Disability (NCPD) joined 22 other national organizations in addressing the disability issues of this case:

It is a well-known fact among those of us who live with disabilities that a feeding tube is a low-tech support, and people who use them can and do live full and meaningful lives. It was invented in the nineteenth century and relies on nothing more than gravity to make it work.

Terri Schindler-Schiavo is characterized as “A brain-damaged woman who has been kept alive artificially.” Meant to signal horror, the concept has no real meaning to us who live by “artificial” means. Is a person on dialysis being kept alive artificially? Is a person taking insulin being kept alive artificially? Is a person who undergoes open-heart surgery, or cancer treatment, or intensive care in a hospital being kept alive artificially?

We call on the general public to join with us in ensuring that the real story about

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Terri Schindler-Schiavo and thousands like her is told. Terri Schindler-Schiavo is alive. She deserves nothing less than the full advantage of human and civil rights the rest of us are fortunate to enjoy as Americans. Can she think? Hear? Communicate? These questions apply to thousands of people with disabilities who, like Ms. Schindler-Schiavo, cannot currently articulate their views and so must rely on others as substitute decision-makers.<sup>1</sup>

The brief and superficial evaluations which earlier pronounced Terri to be in a “persistent vegetative state” or the news headlines characterizing her as in a “coma,” should now be superseded as Mr. Schiavo’s controls over information have loosened. However, these new revelations have been discounted by judges as *history* and missed by the popular press.

Registered Nurse Carla Sauer Iyer noted in a sworn statement: “Terri’s medical condition was systematically misrepresented by Michael. When I worked with her she was alert and oriented on a regular basis.” Iyer was fired when she alerted authorities.<sup>2</sup>

Another sworn statement by Heidi Law, who was afraid for her job because of Mr. Schiavo’s rages when even routine services were provided, tells of sneaking Jell-O to Terri, “which she was able to swallow and enjoyed greatly.”<sup>3</sup>

In the spring of 2000 three physicians reported that Ms. Schiavo is certainly able to swallow since she swallows her own saliva. Then in September, 2002 William M. Hammesfahr, MD, an internationally recognized neurologist, was finally allowed to conduct a lengthy evaluation to ascertain treatment options. He noted: “During 1998 she was evaluated by Dr. James Barnhill, neurologist, who testified that he examined her for ten minutes and determined that she had no chance for recovery and was in a persistent vegetative state . . . One year later he again reconfirmed his earlier diagnosis. He felt no tests of any sort were needed for evaluation.”

Dr. Hammesfahr found Terri is not in a coma; is responsive to her environment, responding to specific people best; tries to please others by doing activities for which she gets verbal praise; differentiates sounds from voices and specific people from others; differentiates music from stray sound; attempts to verbalize; has voluntary control over her extremities in spite of the lack of mobility exercises; can swallow; is partially blind, and can feel pain. “On this last point,” he noted, “it is interesting to observe that the records from Hospice show frequent medication administered for pain by staff.”<sup>4</sup>

And the pro-death advocates for “insensate” people insist the painful death we would not justify for a “non-verbal” dog or cat is appropriate for this neurologically disabled woman.

It is perhaps ironic that I personally understand the negative judgments

made by Mr. Buckley. Previous to 1972 I might have uttered the same words about “insensate” people. I was an intellectual bigot who, as chair of an admissions committee for a graduate program, tossed aside applications from “the handicapped.” Unexpectedly I lost my sight and fell off that ladder of academic success. I landed, protesting and angry, right in the middle of the disability rights movement in Berkeley California.

Resentment evolved into awareness that disabilities result because God’s gift of life comes in very fragile packaging. It seemed increasingly obvious that it is *normal* for the risks, stresses and strains of the living process to result in physiological and neurological glitches. And as I witnessed the interactions between a tiny child lying in a crib and her family—I was there to help *them*—the last vestiges of prejudice about “insensate” or cognitively disabled people fell away. My pride in my superior intelligence had blocked recognition of the lessons this tiny bundle of human life was created to teach. Sarah lay giggling and chortling as her brothers and sisters paused in their play to pat, kiss and caress her as her bodily functions were monitored and attended by multiple tubes. She absorbed and radiated lessons of love with every joyful breath.

**I**t was my increasing disabilities which finally set me free from my prejudices and bigotry. Some people may grow uneasy when I say my blindness was a gift from God. Yet they read of Saul’s transition from persecutor of the early Christians to martyr and saint. It was that gift of blindness that forced recognition that every precious human life is created to illustrate some essential element of His presence in the world.

John Paul II reminded many of us on December 3, 2000 as we joined in celebration of the Jubilee Day of Disability, “By your presence you reaffirm that disability is not only a need, but also and above all a stimulus and a plea. Of course, it is a request for help, but even before that it is a challenge to individual and collective selfishness; it is an invitation to ever new forms of brotherhood. By your situation you call into question those conceptions of life that are solely concerned with satisfaction, appearances, speed and efficiency.”<sup>5</sup>

Terri survives in spite of massive efforts to eliminate her. Many of us who have personally faced medical judgments which threatened our lives are frightened by the discounting of that reality by so many of our fellow Americans of all political persuasions. *We* survive because we *could* fire the doctors who saw no value in our lives or divorce the spouses who wished to profit from our deaths. But will even those of us with loving families soon face the Futile Care judgment which ends routine medical attention? We

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rejoice that our sister, Terri, has a family who has not given up the fight for rehabilitation and medical care she has been denied for over a decade by a man who long ago abandoned her best interests in his union with another woman and their two children. We know Terri's battle, if not joined, can spread to include us all.

Questions need to be asked about the bone scan showing that Terri had been, in a physician's words, "worked over" upon her initial admittance to the emergency room. Friends who said she appeared at work with bruises consistent with abuse need to be interviewed. And some of us think a husband whose actions have come into question would not have ordered immediate cremation of her body before tests could prove he played no role in her disability.

NCPD hears stories every day from people with disabilities and their families highlighting positive lessons that life with disabilities can teach in spite of the pain and suffering involved. While the culture of death tells us how terrible it is to be imperfect, dependent, elderly or disabled, we seek to share those accounts that accompany acceptance of our shared vulnerability. We suggest God in His infinite wisdom places the gift of life into fragile bodies. He means none of us to be complete in ourselves. We are created to need each other and our Lord. The interweaving of our abilities and disabilities; fragilities and strengths; gifts and needs can build the strongest society and church.

## NOTES

1. "Issues Surrounding Terri Schindler-Schiavo Are Disability Rights Issues," Joint Statement signed by 22 national organizations, available at [www.ncpd.org](http://www.ncpd.org).
2. Carla Sauer Iyer, Affidavit of August 29, 2003, State of Florida, County of Pinellas.
3. Heidi Law, Affidavit September, 2003, State of Florida, County of Pinellas.
4. William M. Hammerfahr, medical report signed September 12, 2002.
5. John Paul II, Homily, Basilica of St. Paul-Outside-the-Walls, December 3, 2000, Rome.

# Ordinary Duties, Extraordinary Means

David S. Oderberg

Within morality, there are things a person must do but also many things that it would be beyond a person's moral obligation to do. There are heroic acts, acts that we call "above and beyond the call of duty," acts that are admirable but not strictly required. To take a simple example, if a person can pull a drowning child from a shallow pond with little difficulty, he is bound to do so; but no one is obliged to risk his life by diving into raging surf (unless the person is a lifesaver and it is his job), however much we would admire his heroism if he did so.

This distinction applies across the board, as much in medical ethics as in everyday life. No one is obliged to do what it is beyond his mental or physical powers to do. In general, grave hardship and oppressive burdens can tax a person's capacities, and morality must draw a line between what can and cannot legitimately be expected. On the other hand, doctors have a special expertise that requires them to do things that are not usually expected of a layman. Just as policemen and firefighters, by the very nature of their job, are expected to take risks that others are not, so doctors are expected, by the very nature of their profession, to go to great lengths to save and preserve life.

But how far must they go? They cannot simply ignore the desires of their patients and of the families and loved ones closely concerned, but nor should they bow to every whim and wish. Deciding how a doctor should act in a given situation is often a delicate and subtle task, which decision moralists have the primary responsibility of guiding: moralists, that is, who are not caught up in the death culture that now sadly pervades so much of the medical profession. It is for that profession to listen to and heed the considered opinions of the moral experts who care about life and are trained to balance the competing considerations that must be weighed in difficult cases.

The general ethical principle that must be recognized is that man is morally obliged to adopt all *ordinary* means of preserving health and life. At its most general, ordinary means are those that do not entail grave hardships. If the means do involve grave hardship, they are to be classed as *extraordinary* and hence usually not obligatory. There are exceptions. A person whose continued existence is vital for the common good is obliged to submit to more than ordinary attempts to keep him alive: for instance, a gravely ill

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president or military leader should submit to extraordinary treatment, especially at a time of national crisis. Also, if a person is not spiritually prepared for death, he should submit to extraordinary means to keep him alive until he can be so prepared.

In general, however, submitting to extraordinary means is not obligatory for a patient, hence it is not the duty of a doctor to employ them. We can define ordinary means as including not only food, drink, shelter and rest, but also all treatments and medicines that offer a reasonable hope of benefit for the patient and can be obtained and used without excessive pain, suffering or other inconvenience, including expense, on the part of the patient, his family and loved ones, and the doctors concerned. Means that are not ordinary are extraordinary. Ordinary means are absolutely binding—they must be used, and the failure to supply them is gross negligence. If the failure leads to death, it is morally equivalent to euthanasia.

Food, drink, shelter and rest are ordinary means since there is nothing in the doctor's duty *as a doctor* that makes them special: *any* person is obliged to render another food, drink, shelter and rest if they need it and no hardship is involved in supplying it. But medical expertise brings in other types of assistance that, given the doctor's special knowledge and abilities, are for him, in his situation, what providing food, drink, shelter and rest are for everyone else—a normal duty within the capacity of most people to perform most of the time. The mere fact that the treatment is *artificial* rather than *natural* makes no difference in itself—why should it? Every pill, every injection, every operation is artificial treatment, but many such treatments are ordinary means within the capacity of both patient to undergo and doctor to supply without excessive hardship. There is nothing magical about being artificial that makes a treatment extraordinary. Nor is there anything special about its being expensive, or intricate, or unusual: “extraordinary” in the medico-ethical sense does *not* mean “novel,” “strange” or “atypical.”

Nevertheless, in the circumstances of the case, and according to the definition I gave above, a treatment, whether artificial or not, may be considered extraordinary. Consider artificial feeding. In most cases, such feeding is quite ordinary: the means are ready to hand, easily employed under normal hospital conditions, with no notable inconvenience to patient, doctor, nurses or others involved. Usually it is a *temporary* measure to help the patient get through a difficult period. Sometimes, though, the patient may be terminally ill, or require permanent artificial feeding. Consider the first case. Suppose Fred, a cancer patient, is in unbearable and unrelievable pain, and is being fed artificially. His agony will last a few weeks, but if his artificial feeding is stopped he will die in a few days. Suppose also that he is not

capable of making his own considered request one way or the other. May the physician remove the artificial feeding *in order to shorten the time of Fred's suffering*? Yes, if that were his intention, because the feeding itself conveys no long-term benefit, but does maintain the patient's agony. The patient's suffering in such a case can reasonably be seen as outweighing the loss of a few weeks' life, assuming the patient to be spiritually prepared for death. If he cannot express a wish, his family are permitted to presume that he does not want the feeding to continue (absent other evidence).

On the other hand, whilst this judgment is available in *principle*, in *practice* a doctor should be very reluctant indeed to remove the feeding: (1) there would be, especially in the current climate, a grave risk of scandal—the family and others might well think Fred had been deliberately killed; (2) a doctor who did not understand the subtle moral distinctions in play would be at risk of carrying his behaviour over into cases he regarded as “useless,” as involving lives “not worth living” and so on; (3) the presumption that Fred wants the feeding removed may well be rash—where there is life there is hope, and few people who are ill do not think they just might get better again. Therefore, given the present climate of moral opinion, I would not in general regard the removal of Fred's artificial feeding as permissible.

**W**hat about permanent feeding? The question, again, is whether permanent feeding involves excessive pain, suffering or other inconvenience, including expense, on the part of the patient, his family and loved ones, and the doctor concerned. The usual answer must be that permanent feeding is *not* extraordinary. It usually does *not* cause any suffering, let alone unbearable pain, it is not a major inconvenience either for the patient, family or health care system, and is not in itself a great expense, certainly no more expensive than many of the one-off, costly procedures that are now a routine part of medicine. In each case, however, we must look at the specific circumstances of the patient. Is the patient in a permanent coma, or a persistent non-responsive state, or conscious and responsive but permanently immobile?

In the latter case, as long as the feeding did not cause long-term insupportable pain, how could it be considered anything but ordinary, humane treatment? If we say this about that case, why should a patient in a non-responsive state be treated any differently? Such a person is profoundly incapacitated and dependent, to be sure, but what is the criterion for making a moral distinction, short of making a perverse judgment about which lives are “worth living”? When it comes to permanent coma, on the other hand, intuitions among moralists of good will do differ. Some have held (including Catholic medical ethicists in the 1950s) that a patient in a permanent coma

has no prospect of recovery, and so continuing with artificial feeding does nothing but prolong the distress of the family and divert medical resources that could be more usefully employed.

Karen Ann Quinlan, who had been in a drug- and alcohol-induced coma, died in 1985, nine years after the court allowed her to be taken off a respirator at the wish of her family. Normally, artificial respiration is in the same category as feeding, being the provision of basic assistance with essential biological functioning. Terri Schiavo, on the other hand, requires tube feeding but is quite clearly, as the videos of her demonstrate, conscious and responsive, if profoundly disabled. The cases are factually poles apart—but does that mean there must be a moral difference? Some moralists who have no time for the death culture interpret in a rather broad sense the proposition that to be ordinary, a treatment has to have a reasonable prospect of benefiting the patient: Terri Schiavo is clearly someone who, if her life were maintained by artificial feeding, could well benefit from therapy and be enabled to live a relatively pain-free, comfortable existence; whereas someone like Karen Ann Quinlan had no such hope.

Although I can understand the distinction, it is not clear to me that it licenses the placing of a permanently comatose patient into a different category, ethically, from one who is conscious. Recall that ordinary treatment is treatment that offers a reasonable chance of benefiting the patient. To exclude feeding a permanently comatose person—to say that there is something “extraordinary” about it—on the ground that, although being kept alive by feeding, the patient was still not capable of benefiting from *any additional treatment or therapy*, seems to me to twist the natural meaning of what constitutes ordinary treatment. Assuming they are capable of keeping down food and digesting it, feeding benefits people, whatever state they are in—it does exactly what it is supposed to do. The fact that a permanently comatose patient cannot, if she continues to live, benefit from some *other* therapy that being kept alive by feeding makes possible does not mean that *feeding* does not confer the benefit it is supposed to.

So it is not clear, to me at least, that the “reasonable chance of benefit” criterion applies to feeding any more than to any other treatment or procedure that *in and of itself* has a good chance of benefiting the patient. Contrast this with the case of a patient who is in such a chronic state that he continually vomits up any food administered, is persistently ill from feeding, cannot digest the food, perhaps has severe allergic reactions to the food, and so on—in *that* sort of case feeding might well be extraordinary by virtue of its futility, its discomfort for the patient and its burdensomeness on hospital staff. (Needless to say, such a case would be quite rare.)

It is clear that Terri Schiavo is conscious, can benefit from therapy, and is likely, whatever the results of any therapy, to live (if she is fed) a relatively comfortable existence (in the videos she looks physically to be quite robust). Feeding her is without doubt an ordinary and hence morally binding procedure. What about the distress of family and loved ones? It is indeed relevant, but must always be reasonable. In the Schiavo case, it seems the only “distressed” person is the husband who wants her out of the way; the rest of her family is loving and dedicated to helping her. In general, distress merely because someone is profoundly disabled is not reasonable, at least not reasonable in the sense of constituting a burden that could legitimate withdrawing treatment that was otherwise easy to administer. Comatose patients, however, are slightly different, and I can see why moralists of good will have allowed the withdrawal of feeding in cases where there is palpable distress to the family. A comatose patient *looks* dead and, as far as therapy or family interaction is concerned, might as well *be* dead. If the comatose person has already (while conscious) been spiritually prepared for death, if the family are genuinely seriously distressed by the plight of their loved one, and perhaps if hospital resources are being diverted from more pressing cases where lives can be saved and substantial benefits conferred, then, at least in principle, it might be arguable that feeding may be withdrawn, so long as there is *no intention to kill*.

**I**n practice, however, given the current death-oriented climate, I find it hard to see how a routine practice of withdrawing feeding from permanently comatose patients would not cause scandal, especially when supported by pro-life people who might be thought (falsely) to be licensing a kind of “pro-life euthanasia.” Moreover—and perhaps more importantly—even a cursory examination of the facts about recovery from coma (patients have made a full recovery *years* after the coma began) shows that the diagnosis of permanent coma is often tentative and unreliable, and the principle “where there’s life there’s hope” must be given its due weight. If this is the situation with coma, how much more is it the case with diagnosis of the so-called “persistent vegetative state,” where it is established by empirical research that there is a significant amount of misdiagnosis (43% in one study)? This hardly gives one confidence; added to the ignorance clinicians have of just what is going on inside the head of a person who is not able physically to respond to stimuli, we must conclude that it would be a rash doctor who judged the prospects for such a patient to be certainly dim, especially given the therapies that exist and are constantly being improved. Nevertheless, the best judgment in a particular case might be that certain therapies were not likely



to benefit the patient, and if so there would be no obligation to use them.

Apart from the distress at seeing a loved one in a comatose or other disabling condition requiring constant care, perhaps the two factors that make many people of good will worry about how doctors are to decide upon such cases are the thought of it happening to them and the prospect of great expense with no end in sight. I have already said that distress—*reasonable and properly motivated* distress—is one factor to take into account in deciding whether treatment is extraordinary. Expense—both to family and to the medical system—is another. For one thing, a person does not have to subject himself or his dependants to grave hardship in order to fulfil the duty of preserving life. A family might collectively decide to take on the financial hardship of keeping a loved one on life support (let us suppose the expense is great), even if it involved impoverishing the entire family. But to say that it was obligatory would be too strong, and it would be wrong of a person to impose such an obligation (say, in an advance directive) on his family.

As to the worry that a person might find himself comatose and on life support, and his thinking, “If it were me I’d want them to pull the plug,” we do need to respect that concern. No one *wants* ever to be in that situation, and no one wants to subject their family to such a state of affairs. There is nothing whatsoever wrong—and perhaps it should be encouraged—for people to frame advance directives for what should happen to them were they to end up in such an extreme situation and could not communicate their desires at the time. Without such a directive, the family is generally entitled to assume that the person *would* want everything to be done to keep them alive short of treatment that was immensely painful, distressing, impoverishing or futile. A casual remark made by someone in response to a television show or a newspaper report (“If that ever happened to me, I hope you’d pull the plug”) does *not* constitute evidence of a settled intention; and it is well known that people’s desire for survival can radically change when they finally do face a life-or-death situation. An advance directive could certainly aid decision-making, but would also be superseded should the patient be able to communicate his current state of mind.

No advance directive, however, may contradict morality. A person cannot require extraordinary treatment as an obligation, though he may ask doctors to do as much as they can, even if it involves highly experimental therapies. An advance directive cannot prevent a doctor from concluding, on the best evidence available, that a patient is incurable, and so from ceasing to try to administer a cure. (He should, of course, continue trying to find a remedy for the disease itself, if that is his business.) Further, as long as there is even

a slight hope of curing a patient, a doctor should seek to use every promising remedy at his command, subject to the patient's being free to refuse extraordinary treatment.

A decision about the maintenance of life (note: we are not talking at all about the deliberate *ending* of life, which is murder) must ultimately be made in the best interests of the patient and in accordance with his reasonable wishes, express or implied. Ordinary treatment is a duty: food, drink, nursing care, pain relief. The use of artificial methods of maintaining life are not extraordinary *merely* because they are artificial. In the abstract, there is in general no obligation to use any procedure or administer any treatment that does not hold out real hope of some benefit to the patient. In general, food, drink and life support *do* benefit the patient. Nevertheless, in particular cases they may involve genuine hardship, whether for the patient (to be considered first), the family (to be considered next) and the hospital (to be considered third). If so, then like any other assistance that is extraordinary, they may be withdrawn so long as there is no intention to kill or to shorten life.

Nevertheless, in today's climate of death, where euthanasia is rife throughout the world, where mass murderers masquerading as nurses are regularly arrested and paraded before the media, where shortage of resources is used as an excuse for any sort of medical neglect, where care homes are sometimes no more than cemetery holding bays, and where people increasingly do not want to take responsibility for those under their charge, thinking it is for the "system" to do what it must do, it would be a rash medical ethicist who laid down a blanket permission for doctors to withdraw life-sustaining treatment even where the burden was heavy and the distress difficult to bear. Any decision to withdraw treatment in an individual case must be influenced only by the right sorts of consideration. It must involve lengthy reflection and lengthy consultation with the people directly concerned (including spiritual advisers) and no one else *apart* from (a) experts who can supply objective medical information and (b) experts and advisers who are ethically trained in the right sort of morality and have nothing whatsoever to do with the serial-killer ethic that characterizes much of contemporary bioethics. If there is even the slightest suspicion that the motives of those involved are anything other than pure, withdrawal of treatment cannot be allowed. If there is the slightest risk of scandal, again it cannot be allowed. The position of doctors is now more imperilled than ever—they need as much guidance as they can get.

# A Cup of Cold Water

Stephen Vincent

To feed or not? In the case of an incompetent, unconscious or comatose patient, that is the often vexing question. Who shall speak for him, and on what basis are decisions on life and death, food and fluids, to be made? If a patient cannot eat on his own, must artificial nutrition and hydration (ANH) always be provided as normal comfort care, or is ANH an optional medical procedure?

Mr. Buckley does well to frame his question in a Catholic context, for the Church is a foremost advocate of life. The Church also has a well-developed anthropology centered on free will and the dignity of the human person. Pope John Paul II spent the early years of his papacy laying out his Theology of the Body, which sees human flesh and blood as a divine sign, to the point where God took a body for Himself in the Incarnation.

Yet while affirming the great gift of bodily life, the Church teaches that it is not the ultimate good and death is inevitable. Catholics believe in “death with dignity,” though not in the sense proposed by an organization of that name. Wide is the chasm between killing and allowing to die, though the actions involved in either case may appear outwardly identical, and the result the same. Purpose, intent and hoped-for outcomes sometimes determine, in the Catholic view, what is allowable or not at the end of life.

The direct, intentional taking of life is always prohibited, however, even if done to end suffering or an apparently “senseless” existence (in both meanings of the term). In its 1980 *Declaration on Euthanasia*, the Vatican’s Congregation for the Doctrine of the Faith gave an early warning on the dangers of a materialistic or “quality of life” viewpoint: “It is necessary to state firmly . . . that nothing and no one can in any way permit the killing of an innocent human being, whether a fetus or an embryo, an infant or an adult, an old person or one suffering from an incurable disease, or a person who is dying.” And a patient, even in the throes of painful death, cannot ask that his life be taken, though painkillers may be administered even if they may indirectly hasten death.

The congregation gives a cogent definition: “By euthanasia is understood an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated. Euthanasia’s terms of reference, therefore, are to be found in the intention of the will and in the methods used.”

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Stephen Vincent writes from Wallingford, Conn.

Unjust killing can occur, in this view, by refusing to provide some treatment that is common and effective (such as ANH?) as surely as by pouring poison through an IV tube.

Mr. Buckley cites two famous cases, both involving young women who were judged by some medical experts to be in an irreparable unconscious state. There is the ongoing drama of Terri Schiavo in Florida, whose survival by feeding tube has been protected through an emergency state law. And there is the groundbreaking matter of Karen Ann Quinlan in the 1970s, who lived for years after a respirator was removed.

The questions Mr. Buckley raises are urgent. Indeed the rapid advance of medical science has opened an area of uncertainty requiring further inquiry in Catholic medical ethics. Regarding ANH, the U.S. bishops in their most recent update of directives state that “the morality of withdrawing medically assisted hydration and nutrition from a person who is in” a so-called persistent vegetative state (PVS) has not been determined by the Church’s magisterium and requires “further reflection” (*Ethical and Religious Directives for Catholic Health Care Services*, Fourth Edition, June 2001.)

Yet the tone of Mr. Buckley’s challenge seems at times to proceed from the ambient culture and not from “thinking with the Church.” By saying that Miss Quinlan’s death was “greeted with relief—by everyone,” and emphasizing the strains on a family and the medical community when “an insensate person” who is for “all sensate purposes dead” continues an existence that is “unwelcome by everyone,” he takes the focus away from our duty to the dying. Though “heroic therapy” is not obligatory, as Mr. Buckley points out, quoting Pope Pius XII, the Church does insist on adequate measures and proper intention. The primary focus should not be on the burden of the dying on the surviving, but on care of the patient and the relative burden a treatment may have on *him*. The Church is not oblivious to the burden and suffering that come to family and society from the protracted treatment of “insensate” patients, but these burdens can never be placed above the normal care and concern due to the patient. They can never lead us to see the patient *himself* as a burden, one to be done away with, however mercifully in medical terms.

Contrary to simplistic sources, the Catholic Church does not teach that a person must be kept alive at all costs and with great pain. Compared to the brute debates of the euthanasia crowd, who argue the finer points of putting a plastic bag over granny’s head, the Catholic viewpoint is beautifully nuanced and humane. The inherent tension between the good of life and the unavoidable, often ugly fact of death is tempered by faith in a life to come with God. So while earthly life is a gift and the foundation of all other gifts,

death is the entry to eternal life. In fact, the Church teaches that trying to preserve life at all costs may indicate a denial of God's providence.

The Church teaches that ordinary or proportionate methods of treatment are always obligatory, but extraordinary or disproportionate treatments may be refused. How these terms are defined and applied to actual cases make all the difference. Treatment that seems ordinary and proportionate in one case may be judged extraordinary and disproportionate in an apparently identical case. The same is true as medicine advances and procedures once rare and dangerous become common and relatively safe. Theologians admit as much, and the official statements of the Vatican and the U.S. bishops favor informed consciences making decisions on a case-by-case basis. This is particularly true with ANH.

"There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burdens involved to the patient," reads No. 58 of the *Ethical and Religious Directives*. When does a benefit outweigh a burden, or vice versa, and how are such judgments to be made in emotion-charged circumstances by untrained relatives when a patient is comatose or unresponsive?

The range for conscientious judgment is wide. Pius XII spoke of ordinary means as obligatory "according to the circumstances of persons, places, times and cultures—that is to say, means that do not involve any grave burdens for oneself [the patient] or another." The Vatican's *Declaration on Euthanasia* states, "In the final analysis, it pertains to the conscience either of the sick person or of those qualified to speak in the sick person's name or of the doctors" to decide according to moral norms. If someone seeks a wider latitude than this, perhaps his intentions are not so pure regarding a burdensome sick person.

ANH is a hot issue today because it is not established when it is ordinary and obligatory care. The question is even more contentious than the age-old debate over grace and nature that in centuries past pitted Jesuits against Dominicans. In the present matter, we see Dominican wrestling Dominican. The Winter 2003 issue of the *National Catholic Bioethics Quarterly*, the gold standard of Catholic opinion, carries the lead article, "Artificial Hydration and Nutrition for the PVS Patient: Ordinary Care or Extraordinary Intervention?" in which Dominican Father Joseph Torchia rebuts Dominican Fathers Benedict Ashley and Kevin O'Rourke. The latter pair argue in their 1997 book on health care ethics that ANH may be removed or refused in patients who are in an irreversibly unconscious state, claiming that such

patients, though clinically stable, are really terminally ill. If ANH is removed, they claim, the patients will not die directly from that act of removal but from the underlying illness that causes PVS and prevents them from eating on their own.

Disagreeing, Father Torchia wonders if his confreres are sneaking in a quality of life argument under the guise of a medical assessment. The key question, he states, is “how crucial is the treatment in question to the continuance of the patient’s life and what is the true reason for its withdrawal?”

From my view, inability to eat may be a *symptom* of PVS but good medical care seeks to treat symptoms, especially when failure to intervene results in death by dehydration.

While the Church teaches that ANH is not obligatory when a patient cannot absorb nutrients or the tubes add a burden with little benefit—such as in the case of an imminently dying patient—there must be a “presumption in favor” of providing it. The Schiavo case is instructive. While Church and other religious leaders debated the application of “ordinary” and “extraordinary,” Florida’s governor and legislature passed a bill to keep Terri’s feeding tube connected, explaining that they preferred to “err on the side of life.”

I am neither a doctor nor a theologian, but the words of Jesus resound when I think of ANH: “Whoever gives to one of these little ones even a cup of cold water . . . will not lose his reward” (Matt 10:42). We usually think Jesus is speaking of helpless children, but do we dare exclude the old or comatose? The pro-life movement has always been about widening the net to bring abandoned innocents under the mantle of protection. We must think long and hard before deciding to withhold artificial nutrition and hydration from a patient who might benefit from it—lest in lieu of cold water we offer cold comfort.

“A time to be born; a time to die.”<sup>99</sup>

*David van Gend*

On C.S. Lewis’s gravestone is the Shakespearean quote, “Men must endure their going hence as their coming hither; Ripeness is all.”

Ironically, the quote dates from the untimely death of his mother when he was a young child—it was on the calendar on his father’s desk that day. Doctors today would be as aggressive as needed to pull that young mother back from death. But if Mrs. Lewis had lived to a ripe old age and then declined into a “persistent vegetative state” (PVS), it would not be so untimely if she then developed some life-threatening illness. “Ripeness is all.” Aggressive treatment would not then be seen as the right thing to do. Her dying would not be obstructed.

In other words, we as doctors do factor in the “ripeness” of dying, its timeliness, as to whether we use all available means to prevent death, half-hearted means which will only prevent death if the illness is minor, or no means at all if the goal is palliation, not cure. That is an aspect of clinical judgement which I consider medically and ethically reasonable, yet which rightly causes anxiety for the individual Christian doctor and the pro-life movement.

Can this forum, and subsequent discussion, find some formulation consistent with Christian principles and sentiment whereby we can justify withholding treatment in such a patient who, with aggressive treatment, could probably be pulled back from death to her living limbo? Can we accept that a person’s time is come, and give supportive care and spiritual companionship while they die of their acute illness?

Mr. Buckley asked for “creative, not merely accommodationist” responses to his challenge on the care of persistently unresponsive (or PVS) patients, and while wanting to be creative, I do not want to be misunderstood. I have done battle with Peter Singer and Philip Nitschke and others over euthanasia, and will continue to oppose that cultural corruption of our relations with the frail and infirm—corruption crystallised in the portentous words of Australia’s Governor-General in 1995: “There comes a point when succeeding generations deserve to be disencumbered of some unproductive burdens.” I will likewise oppose the removal of feeding tubes where the patients are not dying and the intention of removing their tube is to make them die.

But my aim is that we reflect more on the line from Ecclesiastes on “a

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time to die,” on “the acceptance of the human condition in the face of death,” as Pope John Paul puts it.

Australia has recently had its first test case on withdrawal of gastric tube (PEG) feeding in a persistently unresponsive patient with advanced dementia. The patient may not have been suffering, but the family was, and they requested removal of the tube as a futile form of “medical treatment.” The court agreed and ordered its removal. Pro-life doctors were divided in their response. Some Catholic doctors were at odds with the Archbishop—who opposed removal of the tube. And in the background hovered the Voluntary Euthanasia Society, relishing the disarray, and playing a cynical game of first supporting the removal of the tube, but then after the event condemning its removal as being a cruel form of slow euthanasia—and urging the swifter, kinder option of a lethal injection.

**T**he key clinical question to ask in such a situation, as I teach my medical students, is whether this patient is stable or dying. If the patient is not dying—and this woman was not dying—then we must not make her die; for as long as it takes we must simply carry her. We can make her die of starvation by removing her PEG, but that is intentional killing, euthanasia.

So the PEG should have remained. That is a heavy-hearted but fairly straightforward decision.

For such patients, however, a less straightforward situation eventually arises. What if the woman above, persistently unresponsive and with tube feeding and all supportive care, then develops an acute illness, such as pneumonia?

The first question is again: “Is this patient dying?” If, on clinical judgement, it is an illness likely to lead to her death, then the decision—the really difficult decision—must be made as to whether we intervene in her dying or not.

Does a doctor always have the duty to rescue a dying patient? One escape clause is that the doctor can withhold treatment which is overly “burdensome,” but to an unconscious patient no treatment can be “burdensome.” Another excuse for non-intervention is that the treatment is “futile” in the sense of ineffective, but intensive antibiotic treatment for pneumonia is likely to be very effective. Is there any other criterion in Christian medical ethics which will justify non-treatment of this PVS patient with pneumonia?

Faced with such a situation, I am fairly sure I would provide palliative treatment only, accepting that she is dying, and not feeling duty bound to obstruct her dying—and I am fairly sure the family (and the patient, in absentia) would be in whole-hearted agreement. But I do so with some



trepidation, lacking a mature body of Christian thought to flesh out what I feel in my medical bones to be the right approach.

This is slippery ground, and can be explored only with great care. But I find hints in various church teachings that the acceptance of a “time to die” may be a positive and permissible component of any reasonable decision to forego further treatment.

For instance, Pope John Paul wrote in *Evangelium Vitae*: “To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death.”<sup>1</sup>

Similarly, wise words from the Pontifical Council for Pastoral Care to Health Care Workers concerning a doctor’s responsibility to his dying patient:

“This responsibility does not always and in all cases involve recourse to every means. It might also require the renunciation of certain means to make way for a serene and Christian acceptance of death, which is inherent in life.”<sup>2</sup>

Those are memorable assertions of the humane over the merely technical. It is technically possible to preserve anybody on life support, and aggressively treat any illness in the unconscious patient. Therefore if we acquiesce in a PVS patient’s dying, it is not because we could not prevent the death, but frankly because we thought it wrong to prevent this particular death. We have not made the PVS patient die—the infection overcame her vital forces. But we have judged, in all seriousness and sadness, that her “time to die” seems to have been reached, and not stood in her way.

Such a “renunciation of certain means,” the Pontifical Council added, “might also mean respect for the wishes of the patient who refuses the use of such means.”

Let us then enquire after the patient’s wishes. The PVS or severely demented patient can, by definition, have no current opinion on the matter. If there is an advance directive, then we can take that into account—and never yet have I met an advance directive that asked to be treated aggressively once a state of irretrievable unconsciousness has been reached. They all “refuse the use of such means,” wanting reassurance that, once their “time to die” has come, there will be no well-meaning interference in the event of an acute illness. Thank you—but no thank you.

Further, since it is an axiom in care of the dying that “the family is the unit of care,” let us enquire of the family. Never have I met a family member who wanted me to intervene vigorously in an irretrievably ill person, such as with PVS or dementia. They tend to say it would be a blessing, that we should let her go to God.

Which brings us to the final interested party. If the patient and family decline treatment, being happy that at last she can go and meet her Maker, do we know if her Maker is happy with our decision?

To my knowledge, there is no Biblical precedent for the PVS patient. Things were tidier in ancient times: you got sick and you died. Yet there is a Christian understanding of death. We are not to despair like those who have no hope. Death no longer has the victory. “And with the morn those angel faces smile, which I have loved long since and lost awhile.” And so on—the revolution in human understanding of death, of your mother’s or son’s or other beloved’s death, since Christ’s resurrection.

Can we as pro-lifers keep the “respect life” flame burning clearly, and opposition to intentional killing unwavering, while making room for “a serene and Christian acceptance of death, which is inherent in life”? Can we reach some peace and consensus about foregoing acute treatment when, as with patients afflicted by PVS or severe dementia, dying is not so untimely?

Accepting that a persistently unresponsive patient is now acutely dying, and palliating their going hence rather than obstructing it, is not to make them die. It is to “accept the human condition in the face of death,” sit alongside them in hope and faith, and watch them go through that dim door where we shall shortly follow.

#### NOTES

1. Pope John Paul II, *Evangelium Vitae*, 1995, n. 65.
2. Pontifical Council for Pastoral Care to Health Workers, *Charter for Health Care Workers*, 1995, n. 121.

## A Duty to Die?

Wesley J. Smith

The culture of death is to society as water is to fish: It constitutes the substance of our environment; it permeates every nook and cranny of our world. In such a milieu, without even realizing it, to one degree or another, we may unconsciously accept some precepts of the death culture without being aware that it has occurred. Before we know it, we find ourselves nodding our heads at assertions that some of us have lives not worth living, and indeed, that in a few cases, killing is an acceptable answer to the problems of human suffering.

We tell ourselves that “compassionate” killing will be rare, that we can effectively corral and control “compassionate” killing to the rare, last resort. But the culture of death isn’t trainable: it does the training. Once we legitimize killing, we become like a once wild but now broken horse directed by its rider to gallop down a steep path toward a dangerous destination where we would not otherwise have gone.

With this in mind, let us explore William F. Buckley’s remarks at the Human Life Foundation’s Great Defender of Life Dinner last October. Mr. Buckley challenged believers in the sanctity of human life to provide “moral illumination” justifying our opposition to euthanasia, implying that by our opposition we ignore the problems associated with greater longevity and impose religious views on an unwilling secular society. “It is simply not arguable,” he asserted, “that in the present age someone who takes his life when, let us say, incapacitated by cancer, is deemed less contumacious than one who does so while in good health.”

But this is quite beside the point. We don’t condemn mercy killing because it is an act of resisting authority. We don’t look down our noses judgmentally at the despairing ill or disabled person who sees self-destruction as her only succor. Indeed, none of us knows our own breaking point. Rather, we resist legitimizing and legalizing euthanasia because it is our moral *obligation* to protect vulnerable people—even from themselves if necessary—and to assert that the lives of all of us retain ultimate value and equal worth.

To resist the suicide of the divorcée, who wants to end her anguish over a broken marriage but sanction her killing if she has cancer, is abandonment. Our human obligation to every suicidal person is to reach out in love, and, to

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borrow from Paul Simon, to be a bridge over troubled waters. And indeed, engaging in suicide prevention for the desperately ill or profoundly disabled is not an empty gesture. Repeated studies demonstrate that terminally ill people often change their minds about suicide when they receive proper intervention and treatment for depression. This was certainly true of a hospice patient with Lou Gehrig's disease I once cared for who had initially been suicidal but came to see his ending days as the best of his life.

From a public policy perspective, opening the door to state-sanctioned private killing—which is what euthanasia laws do—leads with the inexorable force of gravity to suicide on demand. We need only review the history of Dutch euthanasia to see this process in action. The Netherlands has permitted doctors to euthanize patients under what Mr. Buckley called “sensible limitations,” since 1973. In a mere thirty years, Dutch doctors have gone from killing terminally ill people who ask for it, to chronically ill people who ask for it, to disabled people who ask for it, to depressed people who ask for it.

The latter category received the explicit imprimatur of the Dutch Supreme Court in the assisted suicide of Hilly Bosscher, who became suicidal after she lost her two sons, one to suicide in 1986 and the other to brain cancer in 1991. Her marriage, never very good and often abusive, took a turn for the worse after her first son's death and was dissolved in 1990.

Bosscher began to attend meetings of the Dutch Euthanasia Society, where she met psychiatrist Boutdewijn Chabot. She told Chabot that she didn't want therapy, “because it would loosen the bonds with her deceased sons.” Chabot met with her on four occasions between August 2 and September 7, 1991, not to treat her, but rather to determine her prognosis. After these interviews and his consultations, despite the complete absence of any physical illness, he agreed to assist Bosscher's suicide. She died on September 28, 1991.

The Dutch Supreme Court approved of the killing, with the minor caveat that Chabot erred by not having a colleague independently examine the patient, ruling that the law cannot distinguish between suffering caused by physical illness and suffering caused by mental anguish—which, of course, is where the logic of euthanasia leads inevitably. Thus, the “sensible limitations” Buckley extolled embodied in the Dutch guidelines now permit doctors in the Netherlands to kill their depressed patients on the basis of patient demand caused by depression—even if the patient refuses treatment that might overcome the suicidal fixation. (Another example: A Dutch physician euthanized a young woman because she feared returning to anorexic behavior, and the government did nothing.) Again, this isn't compassion: It is abandonment.

Abandonment also comes to mind in the Terri Schiavo case. Mr. Buckley,

perhaps relying on misleading mainstream media reports, seemed to support Michael Schiavo's decision to remove Terri's feeding tube "after years of standing by"—apparently believing him to be a loving husband only interested in his wife's welfare. But that depiction is belied by many disturbing facts, to wit:

- Terri's husband Michael Schiavo has not remained loyal to his wife. He began dating almost as soon as she became incapacitated. Within a few years, he had melted her wedding and engagement rings down and made a ring for himself. He also had her cats euthanized. Since approximately 1996 he has lived and partnered romantically with his "fiancé." The pair has had two children together. In a divorce court, such behavior would constitute marital abandonment.

- Michael Schiavo's attitude toward Terri changed demonstrably after a jury awarded the couple \$1.3 million in a medical malpractice case arising from her injury. During the trial—even though he was quietly dating by then—he depicted himself to the jury as a loving husband who would care for Terri for the rest of his life and who would use much of the money received in the case to pay for rigorous testing and appropriate rehabilitation. After the jury verdict, Michael suddenly reversed himself, refusing to treat Terri's serious infection with antibiotics and claiming that she would not want to live in her incapacitated condition. According to nurse affidavits, he refused all therapy during those years, and medical records show he would not even permit her teeth to be cleaned. Not coincidentally, he would have inherited the approximately \$700,000 in her trust fund had she died when he began the case to end her tube feeding.

- Judge George Greer of the Sixth Judicial Circuit apparently has such little regard for the equal worth of Terri's life that he has refused to abide by Florida law intended to protect her rights. For example, Florida law requires that Michael Schiavo, as Terri's guardian, submit an annual plan for court approval describing the ward's needs and the guardian's plans to meet them in the coming year. This annual plan is deemed so essential in Florida law to the proper protection of incapacitated persons that a guardian's authority *depends* on and is limited by, court approval of the terms in the plan. Despite this, Judge Greer has allowed Michael Schiavo to serve as guardian with *no annual plan in place since July 1, 2001*.

- Credible medical evidence has been presented that Terri might—with proper rehabilitation—be able to be weaned from her feeding tube. Yet Judge Greer, giving the benefit to her death rather than her life, even refused to permit this therapy to be attempted.

Many either are unaware of these and other injustices or shrug them off as

being inconsequential because the depth of Terri's disability interferes with their ability to accept her as a fully equal and morally worthy human person.

Mr. Buckley also appeared to advocate ceasing life-sustaining treatment to avoid "exposing surviving loved ones to the sundering emotional drama of living with someone as though alive, though for all sensate purposes dead." The great Christian theologian and bioethicist Paul Ramsey, a strong believer in the moral equality of all human life, warned against falling into this trap. Writing in his seminal *The Patient as a Person*, Ramsey asserted that we all owe each other a duty of fidelity and "covenant responsibilities" based in "justice, fairness, righteousness, faithfulness, canons of loyalty, the sanctity of life, *hesed*, *agape* [steadfast love], or charity."

Rather than making medical decisions for the incapacitated based on what might seem best for others, Ramsey argued that only the "objective medical condition of the patient" should be considered when determining whether to cut off treatment, "not the subjective, capricious, and often selfish evaluations of the quality of future life that are often to the detriment of the most vulnerable and voiceless." Thus, when someone is actively dying and their body can no longer assimilate food and water, refusing tube feeding would be humane and proper. But denying patients food and water because their lives aren't deemed worth living would be morally wrong.

Ramsey's prescription not only makes sense from a moral perspective, but as a prophylactic to prevent the slide down a slippery slope to the societal creation of a caste of disposable people. Unfortunately, Ramsey's views are denigrated as passé in contemporary bioethical thinking. Indeed, the bioethics movement's predominate dogma explicitly asserts that some of us have higher value than others, a discriminatory approach to measuring the value of human lives known as "personhood theory."

According to this view, humans have no intrinsic moral worth. Rather, each of us must earn our moral value by demonstrating sufficient cognitive capacity to qualify as "persons." Those whose rationality or perceived level of sentience do not measure up—for example because they are not self aware over time—are denigrated as "non-persons," and stripped of their human rights to life and even, bodily integrity.

Who are the human non-persons in this philosophical view? Clearly, Terri Schiavo qualifies for the denigration—whether or not she is actually unconscious—because her cognitive capacities appear so limited. Similarly, patients with advanced Alzheimer's disease also lose their personhood, meaning that to many bioethicists, former President Ronald Reagan is no longer a person. Moreover, not only are all unborn humans non-persons under this theory, but many proponents of personhood theory assert that newborn infants

aren't persons either, thereby justifying infanticide. (To avoid this result, some bioethicists call newborns "potential persons," and urge that they be treated as if they were persons based on their future personhood potential.)

This all leads directly to a "duty to die"—an odious concept already being actively discussed in bioethics discourse. Under this theory, it is immoral to depend significantly or extensively on others for our care. As bioethicist John Hardwig argued in the *Hastings Center Report*, "A duty to die is more likely when continuing to live will impose significant burdens—emotional burdens, extensive caregiving, destruction of life plans, and yes, financial hardship—on your family and loved ones. This is the fundamental insight underlying a duty to die."

Thus, just as the longest journey begins with the first step, our road to the abyss begins with a belief that the lives of the very sick and profoundly disabled deserve less protection than those of the rest of us. Killing, sold initially as compassion for others, eventually becomes a tool of selfishness to ease the burdens in our own lives.

Yes. These issues do indeed require klieg lights of moral illumination. But definitely not the conclusions Mr. Buckley seems to have reached.

# Saving Terri Schiavo

*Audrey Ignatoff and Vickie Travis*

**A**t exactly 3:25 p.m. Eastern Standard Time on October 21, 2003, wild screams were heard in a quiet suburban town in central New Jersey and, simultaneously, in a quiet desert community in southern California. Two women were yelling, “We did it; we actually did it! We helped to save Terri Schiavo!” The two women were ourselves, Vickie Travis and Audrey Ignatoff, and we were exhilarated at having been part of the worldwide Internet effort to save the life of the disabled Florida woman whom a judge had sentenced to death by starvation and dehydration. We had just been listening to a live radio broadcast from the Florida Legislature at the moment when the final vote of the Florida Senate came in, concurring with the House to reinstate Terri Schiavo’s feeding tube, which had been removed by court order six days before.

Make no mistake about it, Terri’s Law represented a great victory, not only for Terri Schiavo and her family, but also for all people concerned with patients’ rights and the quality of health care in America. It resulted from a nonstop worldwide Internet effort that began in the early morning hours of October 11 and continued until the vote came in.

October had been an emotional roller-coaster for Terri’s supporters. On October 10, Judge Richard Lazzara of the Federal District Court in Florida was due to rule on Judge George Greer’s September decision to remove Terry’s feeding tube. Many of these supporters were so sure the case would be settled in Terri’s favor that they relaxed a bit the week before October 10, and even took the time to produce a video of Terri, using still pictures from her website and some video footage sent from Florida. Thus, when Judge Lazzara stated that the case was not in his jurisdiction, the blow landed all the harder.

The Internet ride had started gaining momentum even before then when “Dawn,” a psychotherapist and mandated abuse reporter who prefers not to be identified, called in to the Highway 2 Health Internet radio program to ask, “Where are the mandated abuse reporters in Terri’s network?” Many states have instituted programs through which suspected child abuse can be reported—by trained “mandated reporters”—and investigated. Some states, of which Florida is one, extend this program to adults who are vulnerable by

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reason of disability or illness. In Florida, statute 415.103 addresses this question and permits intervention. Even before Terri's husband, Michael Schiavo, requested a court order to kill her by withholding food and water, he had, according to nurses and other credible witnesses, refused to let her enter rehabilitative therapy and had even forbidden the use of antibiotics to treat an infection. This, as Dawn put it, "is physically and psychologically abusive and meets criteria for mandated intervention."

Dawn pointed out that whereas coverage of Terri's case has focused on right-to-die issues, in fact the real issues at the heart of Terri's case are about right to treatment and enforcement of this right. She added: "Terri's moral and legal right to treatment supersedes the guardian's right to deny same."

Dawn was intense. "Homicide is not an acceptable treatment modality. . . . It's not okay to deny treatment to people and then proceed to terminate them because they didn't get any better, which is essentially what is being contemplated in Terri's case. What kind of a 'treatment option' is this?"

While Dawn, Audrey, Vickie, Highway 2 Health, The Hospice Patients' Alliance, and many other groups and individuals worked frantically to help Terri, the judicial machinery ground on. As stated above, on October 10 Judge Lazzara ruled that he did not have jurisdiction to protect Terri's right to treatment. In the early hours of October 11, Dawn meditated and prayed, seeking a way to achieve maximum impact within a very limited timeframe.

Soon she felt guided to intensify the effort she had begun on that Highway 2 Health program to conceptualize the issues as right to treatment and enforced protection of that right when necessary. Some medical professionals believe that the feeding tube would not be an issue today if Terri had gotten proper treatment 14 years ago, when the initial brain injury occurred, and throughout the intervening years.

Now, in October 2003, a three-phase emergency intervention campaign evolved. Dawn soon had help from Christina, Dee, Donna, Kathy, Margaret, and Rebecca from Terri's Internet prayer pages, and from us, Vickie and Audrey; we all jumped on board to get Phase One in gear within 48 hours.

Phase One was a letter to Florida Governor Jeb Bush asking him to back up the amicus brief that he had filed on October 7. That brief had stated that forbidding oral sustenance is the "deliberate killing" of a human being, which violates the patient's "right to life" under existing Florida law. Now, after Judge Lazzara's ruling, Governor Bush was urged to enforce protective measures to assure Terri's right to treatment, not termination, and he was reminded that there are statutes on the books empowering and indeed requiring him to do so. The campaign urged people to contact Bush and the media by e-mail, fax, and phone.

On October 13, with no visible sign of life from the governor's office, Dawn took the intervention up a notch. In Phase Two, she urged people to immediately file abuse reports at the Florida Abuse Hotline re Governor Bush's failure to enforce Statute 415.103.

On October 15, in accordance with Judge Greer's ruling, Terri's feeding tube was removed. Judge Greer had also ordered that she not be fed or given water by mouth, although witnesses testified that she did have the ability to swallow. On October 17, Judicial Watch filed an abuse report and also sent a letter to the Governor about the need to intervene.

Phase Three began on October 18, three days into the deliberate attempt to starve Terri Schiavo to death. Now the focus was further refined, with a specific request to Governor Bush that he address the Judicial Watch complaint. Letters were also sent to the governors of every state, the press, and members of the Florida legislature. These letters pointed out that the Governor of Florida had the power to back up his amicus brief because of laws already on the books to protect the disabled and other vulnerable people.

**B**y this time, an international network known as "Terri's Angels" had formed, dedicated to working around the clock to save Terri's life.

Jeb Bush could not ignore the tons of e-mails pouring in from all over the world. The numbers ballooned from 27,000 to well over 167,000. In addition, there were faxes and phone calls coming in all day long. In short, public pressure paralyzed the Florida government, which had to do something, and quickly. Governor Bush issued the following statement, "Today I extended the call of this special session to include legislation that may help in the case of Terri Schiavo. The proposed bill would allow for a stay in cases of withholding nutrition and hydration from patients in situations similar to that of Ms. Schiavo." The legislature responded and passed Terri's Law—and not a moment too soon. By the time the law was passed, Terri had had no food or water for more than 6 days. Even Wesley Smith, the tireless anti-euthanasia activist, had been ready to give up. On October 12, he stated in an e-mail to Ms. Ignatoff, "I am at a loss. I fear our only approach now is to hold vigil so our sister does not die alone."

Terri's Angels were greatly aided by Ron Panzer of the Hospice Patients Alliance ([www.hospicepatients.org](http://www.hospicepatients.org)), who vigilantly reported all aspects of the case. He was ready to call a worldwide boycott of Florida products and services if Terri's Law was not passed. His newsletter goes out on the Internet to many subscribers. Many of his Internet articles reached Florida newspapers. The wider media eventually became interested in this story, although they did not report all of the facts accurately.

Peter Kawaja, of Highway 2 Health ([www.highway2health.net](http://www.highway2health.net)), ran shows on Terri's case way before it was covered by Bill O'Reilly, Larry King, and Oprah. In fact, Peter ran a two-hour special on October 1 that included Terri's father, Bob Schindler, and various activists in the field, including Ron Panzer and Vickie Travis. Vickie suggested that listeners "follow the money trail" to learn why such things happen to Terri and other victims.

Wesley Smith also spoke on Highway 2 Health, calling Terri's case another step on "the slippery slope from assisted suicide to legalized murder." With perfect timing, an article by Smith came out in the *Weekly Standard* on October 21, the very day that Terri's Law was passed. In it, Smith wrote, "When Terri Schiavo collapsed in 1990, causes unknown, she could have had no idea that 13 years later people the world over would know her name and care very much about whether she lived or died. Yet what began as a private tragedy—a vivacious young woman stricken in the very prime of her life with a brain injury that left her profoundly disabled—has become a story heard round the world." Supporters did indeed call in from all over the world, including Canada, England, Australia, Germany, and Israel.

Diane Coleman of Not Dead Yet, a coalition of advocacy organizations for the disabled, went to Florida and joined the vigil. Her organization submitted an amicus brief on Terri's behalf. In a press release, Coleman stated, "We call upon the courts and medical profession to give Terri Schiavo the full protection of due process of the law before starving her to death and pretending it to be an act of 'dignity' and 'respect for autonomy.'"

The fight to keep Terri alive is still going on.

Meanwhile, Terri has been transferred from the Hospice of the Florida Suncoast in Pinellas Park to Park Place of Clearwater, Florida, an assisted-living facility, where she remains on a feeding tube but is not receiving any therapy. Her parents are circulating a petition on the Terri Schindler Schiavo Foundation's website ([www.terrisfight.org](http://www.terrisfight.org)) directed toward Florida State Attorney Bernie McCabe, requesting him to investigate Michael Schiavo's actions with regard to Terri.

Meanwhile, Michael and his lawyer, George Fellos, are still engaged in their campaign to "let her die" because that is "her wish." (Interestingly, it took Michael fully ten years after Terri was stricken to "remember" that she did not want to live any more if she were disabled.) They are challenging Governor Bush in the courts, saying he interfered with Terri's "death process" and claiming that Terri's Law is unconstitutional. Schiavo claimed on national television that "right to life" groups and "right wingers" are behind the fight to save his wife. He also alleged that Terri's parents want to keep her alive because she makes money for them. In fact, Michael received a

very large monetary settlement from his malpractice suit early in Terri's ordeal. As for Terri's Angels, most are not wealthy but have contributed hard work, hope, and prayers.

Terri Schiavo is neither in a "persistent vegetative state" nor "comatose." Her family notes—and they have smuggled camcorders into her room to document their claims—that a person in such a state would not respond to people and objects as Terri does. Many physicians, including neurologists, agree. Sara Green Mele, a speech pathologist, feels that Terri would benefit from speech-language and physical therapies. She states, "Her quality of life would be significantly enhanced."

Florida's Advocacy Center for Persons with Disabilities (ACPD) was summoned by the supporters of Terri Schiavo to do their job of protecting Terri by looking into abuses inflicted by her husband, including withholding therapy and keeping her isolated from family and friends. Terri was even denied Holy Communion and Last Rites from her priest, Monsignor Thaddeus Malanowski, before her feeding tube was removed, and a holy medal that was blessed by the Pope was taken away from her.

Michael Schiavo persists in his effort to end his wife's life, while her supporters doggedly fight to save her. However aware Terri herself may or may not be, she has become the world's most powerful advocate of patients' rights and the rights of the disabled, with ramifications affecting the whole health-care system.

Governor Bush and the Florida Legislature had to be pushed, but they should be congratulated for finally acting on behalf of Terri Schiavo and all other disabled people. As the Speaker of the Florida House, Johnny Byrd, put it, "... someone needs to be a voice for the voiceless like Terri Schiavo."

The ride on the Internet was indeed wild. It developed a life of its own that was stronger than any individual or group in the effort to save Terri Schiavo. It was well worth the trip.

## Ronald Reagan's Clarion Call

Mark Pickup

In 1982, "Baby Doe" was born in Bloomington, Indiana. The baby had Down's syndrome and a defect of his esophagus that needed corrective surgery before he could drink from a bottle. The surgical procedure was considered routine for children born with the condition known as trachea-esophageal fistula. But because Baby Doe had Down's syndrome, his parents decided to refuse the surgery and allow the wee child to starve to death. When the situation became public, several couples offered to adopt Baby Doe and even pay for the surgery. But the parents, their doctors, and an Indiana Court said they had a right to refuse medical treatment in order to starve him. That's exactly what happened, and Baby Doe died seven days after being born.

Decent people across America (and the world) were appalled at this horrible injustice—including President Ronald Reagan. The next year the President wrote an article for the *Human Life Review*, "Abortion and the Conscience of the Nation," in which he dealt directly with his horror over the case of Baby Doe. It was President Reagan's correct view that abortion concerns every person because all humanity is interdependent. To illustrate this point, the President quoted English poet and divine, John Donne (1572-1631) who wrote, "... any man's death diminishes me, because I am involved in mankind . . . ." This is part of Donne's 17th Meditation from *Devotions upon Emergent Occasions* (1623). Those words follow the immortal line, "No man is an island entire of itself; every man is a piece of the Continent, a part of the main . . . ." Humanity's interdependence makes the welfare of one person the concern of all people. America, Reagan was saying, was not made up of 300-million little islands entire unto themselves. Words like "family," "citizen," "community," "neighbor," and even the *United States of America* attest to human interdependence. And that human interdependence included disabled and helpless Baby Doe.

The President continued:

"We cannot diminish the value of one category of human life—the unborn—without diminishing the value of all human life. We saw tragic proof of this truism last year when the Indiana courts allowed the starvation death of 'Baby Doe' in Bloomington because the child had Down's syndrome."

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The great man was deeply troubled. “The real question today,” he insisted, “is not when human life begins, but, *What is the value of human life?*” He reminded readers that America was founded by men and women “who shared a vision of the value of each and every individual.” The President said that this vision was clearly evident from the beginning with those towering words of the Declaration of Independence: “We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable rights, that among these are the right to life, liberty, and the pursuit of happiness.”

The President wrote: “Regrettably, we live in a time when some persons do *not* value all human life. They want to pick and choose which individuals have value. Some have said that only those individuals with ‘consciousness of self’ are human beings. . . . Obviously, some influential people want to deny that every human life has intrinsic, sacred worth. They insist that a member of the human race must have certain qualities before they accord him or her status as a ‘human being.’”

With clarity and conviction President Reagan held that it was important for America’s future that the country re-embrace the sanctity of human life ethic. “My administration is dedicated to the preservation of America as a free land,” he concluded, “and there is no cause more important for preserving that freedom than affirming the transcendent right to life of all human beings, the right without which no other rights have any meaning.”

His words carried an ominous tone for the future regarding definitions of worthy life of “some influential people” that would discount the intrinsic value of the cognitively disabled. Little did he know that a decade later he himself would join this group of people whose intrinsic value was/is being discounted.

#### **One grey November day**

On a dreary, grey day in November of 1994, Ronald Reagan told the American people he had Alzheimer’s disease. Friends and foes alike were stunned at the news. It was a fate one would not wish on his worst enemy. With his irrepressible optimism, class, courage and dignity the former President expressed his love of America and gratitude to the American people for allowing him to serve as their President. Rather than focus on himself, Mr. Reagan expressed concern about public awareness of this awful disease which afflicts millions of Americans. He called upon the goodness of Americans to support those families enduring the painful journey of losing a loved one to the disease. Of his beloved wife Nancy, Ronald Reagan lamented, “I only wish there was some way I could spare Nancy from this painful

experience. When the time comes, I am confident that with your help she will face it with faith and courage.” His faith in her *was* well placed: Throughout their soul-wrenching journey with Alzheimer’s, Mrs. Reagan has remained by him—steadfast in faith and courage—just as he knew she would be.

By extension from his own situation, I believe that Ronald Reagan was appealing to the best part of America to rally around families of people with profound disabilities in an embrace of a community of comfort and affirmation. Ronald Reagan finished his sad announcement to the American people by saying, “I now begin the journey that will lead me into the sunset of my life. I know that for America there will always be a bright dawn ahead. Thank you my friends. May God always bless you.”

With those eloquent words, America’s 40th President retired from public scrutiny: the steady decline of Alzheimer’s disease awaited him.

Ronald Reagan’s imagery of entering the sunset of his life was historically poignant. In 1787, a Constitutional Convention assembled in Philadelphia to make a Constitution defining how America would govern itself. It was no easy task. There was much division and heated debate, but eventually the Convention members had an instrument they could support. As the last members were signing the constitutional document, Benjamin Franklin looked toward the President’s chair. Behind it was a painting of a sunrise. Doctor Franklin commented to a few members near him that painters often find it challenging in their art to differentiate a rising from a setting sun. Then Benjamin Franklin said:

“I have often and often, in the course of the sessions, and the vicissitudes of my hopes and fears as to its issue, looking at that behind the President, without being able to tell whether it was rising or setting; but now at length, I have the happiness to know, that it is a rising, and not a setting sun.”<sup>1</sup>

One hundred and ninety-six years later Ronald Reagan spoke of the setting sun of his own life—and I worry. I worry that the analogy the great wordsmith chose for himself will apply to the greatness of America too. As the President would say if he could, the sun will set—perhaps never to rise again—if her people abandon the self-evident truth and founding principle: the sanctity of all human life.

#### **Missing the clarion call and its disastrous implications**

Unfortunately, a significant segment of American society did not respond to Ronald Reagan’s clarion call. In the twenty-two years since he wrote his article for the *Human Life Review*, America has yet to excise the malignancy of *Roe v. Wade*. That dreadful Supreme Court decision not only opened Hell’s

gates wide to abortion on demand across the land; just as insidiously, it began to mutate the public mindset to consider what had previously been unthinkable: Killing human beings who are inconvenient, burdensome, unloved, despairing or whose disabilities fall below an arbitrary level of acceptability. *Roe v. Wade* was not just pernicious, it was pervasive.

### Lies of the heart

The worst lies are lies of the heart—they rot the souls of men and nations.

We now know that the 1973 *Roe v. Wade* Supreme Court decision that struck down all state laws restricting abortion, was based on a lie. Jane Roe was actually Norma McCorvey and her pregnancy resulted from romance, not gang rape, as was claimed at the time. In the years that followed *Roe v. Wade*, McCorvey experienced a dramatic change of heart and moral conviction that often follows Christian conversion. For quite some time, McCorvey has been seeking to re-open her now despised court decision, and set the record straight. Perhaps she will get her chance. A federal appeals court has agreed to hear arguments by McCorvey to overturn the landmark decision. “All I did was lie about how I got pregnant,” McCorvey says. “I was having an affair. It all started out as a little lie. I said what I needed to say. But, my little lie grew and grew and became more horrible with each telling.”<sup>2</sup>

Abortion advocates had been preparing the public to accept the necessity of abortion for years before the High Court’s decision. They effectively conjured graphic metaphors of rusty coat-hangers and back-alleys and said that thousands upon thousands of women died each year at the unscrupulous hands of criminal abortionists. U.S. Surgeon General, C. Everett Koop finally set the record straight on this fiction:

Undocumented statements, subsequently acknowledged as unfounded in fact, were endlessly repeated until they acquired a ring of truth. Sincere and concerned people were disturbed; they were purposely misled. Thousands of women were said to be dying each year at the hands of criminal abortionists. Some estimated 10,000 women died each year of illegal abortion—others said 5,000. The United States Public Health Service, however, reported from all abortions *legal and illegal*, 189 deaths in 1966, 160 deaths in 1967.<sup>3</sup>

According to the U.S. Bureau of Vital Statistics, in 1972, the year before *Roe v. Wade*, 39 women died from illegal abortions in America.<sup>4</sup> Suffice it to say that abortion advocates *slightly* inflated the numbers to falsely shock the public into thinking there was a virtual holocaust of desperate women dying in back-alleys. As regrettable as the 189, 160, and 39 deaths were, the oft-quoted assertion that thousands upon thousands of women were dying each



year in America from botched abortions was simply not true. One thing is certain: After the 1973 abortion decision, an unfathomable holocaust of children began, the likes of which nobody could have imagined, even in their darkest nightmares. For millions of babies, wombs became killing fields. Did anybody actually believe the killing, once unleashed, would remain confined there?

By the time the Baby Doe case became public in 1982, withholding medical treatment, nutrition and hydration from Down's syndrome newborns had become routine medical practice. In the December 1982 issue of *Archives of Internal Medicine*, Dr. Norman Fost, a Professor of Pediatrics at the University of Wisconsin, wrote, "It is common in the United States to withhold routine surgery and medical care from infants with Down's syndrome for the explicit purpose of hastening death." Newborns with other handicaps receive similar treatment, as was noted in a 1983 report of the President's Commission for the Study of Ethical Problems in Medicine.<sup>5</sup> In subsequent years, more incremental advances of evil could be noticed in euthanasia and assisted suicide acceptance.

#### **Promoting death from behind the respected robes of academe**

In 1998, Australian bioethicist Peter Singer was appointed DeCamp Professor at Princeton University's Center for Human Values. With the authority, respect and prestige of Princeton behind him, Singer contends that, regardless of species, there are two crucial attributes necessary to being a person: rationality and self-consciousness. By these criteria, persons include whales, monkeys, dogs, pigs, cattle, and so on. But according to these criteria, Ronald Reagan's advanced Alzheimer's disqualifies the former president from enjoying the same moral worth as a pig or a dog. In his ground-breaking book, *Culture of Death: the Assault on Medical Ethics in America*, Wesley J. Smith says about Peter Singer's philosophy: ". . . some humans would not be persons, including newborn human infants, whether disabled or not, and people with advanced Alzheimer's disease or other severe cognitive disabilities—people whom Singer claims are not self-conscious or rational."<sup>6</sup>

Later Smith clarifies Singer's intent:

"What Singer contends is that the moral worth of lives—whether animal or human—is roughly equal to their cognitive abilities. . . . Thus, Singer appears to believe that given the choice between saving the life of a dog and a mentally retarded human being, we should choose Fido."<sup>7</sup>

#### **An elephant in the room?**

When people avoid an obvious discussion, it's like an elephant—that nobody acknowledges—is in the room. Let's get to the point. According to

Singer's own standards, Ronald Reagan is no longer a person! And according to the bioethics of Peter Singer, America would deny the former U.S. President his humanity or even basic medical care due to his advanced Alzheimer's disease. A Singerite disciple might respond that when Mr. Reagan was a person he amassed a fortune that will allow his family to treat him with the dignity afforded to real persons who have rationality and self-awareness. Precisely. The brutality of utilitarian medicine espoused by the Peter Singers of this world comes into sharper focus: The rich, loved Alzheimer's patient would get care; the poor, unloved person with Alzheimer's or any other cognitively disabled American would be killed. Welcome to the America of Princeton's Johnny-come-lately.

#### **Parallels between Baby Doe and Terri Schiavo**

The parallels between Baby Doe and Terri Schiavo are worth noting: Both cases involved mentally disabled people—one a newborn infant, the other an adult woman. Both cases involved the desire of immediate family to kill a handicapped member. Both cases had complete strangers offering to take care of (even adopt) Baby Doe and Terri Schiavo. Both cases involved court-sanctioned starvation/dehydration killings. Both cases presumed the individuals were better off dead than living disabled. In fact, at a 1993 deposition, Terri's husband, Michael Schiavo, stated under oath, "... she's a total quadriplegic. Okay? In my own feelings, if Terri were to wake up and see herself the way she is now, she wouldn't even want to live like that." In other words, it is better to be dead than disabled. But that's how a strapping, healthy, strong man felt looking at someone else with a serious disability. Michael Schiavo only knew the twenty-six-year-old Terri of yesteryear.

Am I suggesting Terri *would* want life as a quadriplegic? Yes I am. Oh, maybe not at first. I can certainly understand that if Terri had awakened to find herself a quadriplegic she might initially want to die. What a terrible shock! After all, she was young, vibrant, and beautiful; the American dream stretched ahead of her. Then overnight her world was turned upside down. Of course she might despair of life for a period of time. Nobody who is able-bodied wants to live as a quadriplegic—yet thousands of people go through the despair and go on to live full and contented lives in that state. Attitudes of people with disabilities change over time. What is utterly overwhelming today, may not be tomorrow, next year or ten years hence. Canadian rehabilitation counsellor Walter Lawrence (himself a quadriplegic) commented on the changing attitudes of people toward their disabilities, their perceptions of quality of life (or lack thereof), and an accompanying desire to die: "What I see in rehab is that 90 percent of all high lesion spinal

cord injured persons want to commit suicide. After five years of living with a spinal cord injury, 5 percent contemplate suicide. It is a drastic change.”<sup>8</sup>

Quality of life is a moving target!

There is no reason to believe things would be different for Terri.

#### Quadriplegia by the installment plan

Twenty years ago I was healthy, strong, agile and athletic. I would have recoiled in horror at the thought of living with progressively degenerative disease; yet in 1984, that’s exactly what happened. I was diagnosed with multiple sclerosis (MS). Today, I move about in an electric wheelchair; my right arm is becoming increasingly useless. My left arm is the only remaining limb unaffected by MS. Unless there is some way of stopping this terrible disease, quadriplegia is a distinct possibility for my future. I do not want to live as a quadriplegic. But do not construe what I’ve just said as a desire to die or that I believe life cannot be complete without the full use of my limbs. I am entering an advanced stage of multiple sclerosis and even my few remaining functions may yet be stripped from me. In fact, my future may be worse than Terri’s Schiavo’s present. I don’t want to live like that. The same may be true for Terri. Terri may not have wanted to live as a quadriplegic, but that does not mean she would be better off dead. And even if she wanted to die in 1993, she may feel different in 2004. We just do not know how people will feel after the shock, after the despair, after the grieving subsides. Human beings are resilient and most will redefine themselves within their new realities.

Physical function is not the final arbiter for the value of a life. Quality of life is not the final criterion of human value. Love is the final criterion of life. It is Divine love not romantic love that creates life in God’s image. It is Divine love that sanctifies every human life, not sentimental affection. To know Divine love, and to love the Lover is what gives life meaning. If that is true, then Terri Schiavo and Ronald Reagan win hands down. Granted, humanly speaking there are people who do not value them, but others do. Terri Schiavo is loved and valued by her parents, her siblings and tens of thousands of people across America—most of whom she has never met. Ronald Reagan is loved by his family, and millions of his fellow-Americans—most of whom *he* has never met.

If Ronald Reagan were to write a follow-up article to his 1983 article for the *Human Life Review*, I believe his tone would carry a new sense of urgency—even desperation—for America’s future. Like the crew of the sinking *Titanic* sending flares up into the sky, Mr. Reagan would be calling his fellow citizens back to his beloved America’s original vision of the sanctity

## MARK PICKUP

of human life ethic. I think he would point to it as a solid foundation for human rights and true human equality. America must see the flares that her fortieth President is too sick to send. It must once again embrace the sanctity of human life ethic, lest it lose its way, flounder on high seas of the twenty-first century, and sink into history.

## NOTES

1. Benjamin Franklin, "Franklin on the Constitution" in Readings in World History, ed. Leften S. Stavrianos (Boston: Allyn and Bacon, Inc., 1962), p.258.
2. Quote Taken from Minnesota Concerned Citizens for Life webpage [http://www.mccl.org/fp\\_news/mccorvey.htm](http://www.mccl.org/fp_news/mccorvey.htm) , accessed 18 February 2004.
3. C. Everett Koop, *The Right to Live The Right to Die* (Wheaton, Illinois:Living Books, 1982), p.36.
4. From the U.S. Bureau of Vital Statistics Center for Disease Control, as cited in Dr. and Mrs. J. C. Wilke, *Abortion: Questions and Answers*, rev. ed. (Cincinnati: Hayes Publishing, 1988), pp. 101-2.
5. Quoted from Nat Hentoff, "The Awful Privacy of Baby Jane Doe," <http://www.web.syr.edu/~syndrake/hentoff.htm> ; accessed 9 February 2004.
6. Wesley J. Smith, *Culture of Death: The Assault on Medical Ethics in America* (San Francisco, California: Encounter Books, 2000), p.15.
7. Smith, 192.
8. Jennifer L. Piccolo, "Too high a price to pay for hope: MS sufferer's principles lead him to reject stem cell transplant," *The Washington Times*, 21 June 2001, A1.

# Twenty Propositions

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## Introduction

The patient who is persistently unresponsive (sometimes referred to as “vegetative” or “comatose”) poses particular ethical difficulties in relation to whether to continue feeding, particularly when the evidence indicates that the state is permanent.

In Melbourne, this matter came to a head with a recent Victorian Supreme Court review of a decision by the Public Advocate and a tribunal to allow a patient’s husband to withdraw feeding through a Percutaneous Endoscopic Gastrostomy (PEG Feeding). The patient, known as BWV, had advanced Pick’s disease, a degenerative brain disorder disease that is characterised by the circumscription of the atrophy to the upper brain. She had been fed via a PEG for more than three years.

Because she is unable to swallow any food or fluid given by mouth, she is doubly incontinent, that is of bladder and bowels, and spontaneous emptying of these organs occurs through the action of spinal reflexes. As a result the patient now requires to be moved by a hoist to the shower and after cleaning there is an application of pads, to protect her skin as far as possible.

She requires regular avoidance of pressure, having previously developed some pressure ulcers which were healed as a result of the excellent care she had received in the hospital; they remain a threat of recurrence as a result of her continuing deterioration. She has no cognitive capacity at all and appears to be unable to appreciate any painful stimuli<sup>[1]</sup>. She is incapable of any movement but will follow with her eyes anyone who comes to her bedside.<sup>2</sup>

There are many cases concerning patients in similar states in courts and before ethics committees throughout the world. There is some significance, however, in the fact that Pick’s disease follows a predictable course of atrophy to the upper brain and it is incurable. Faced with that prospect early on in the disease process, patients may well be able to issue an informed and competent direction about their care, in advance, based on an accurate prediction of the eventual nature and progress of the disease. There are efforts being made in

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Western societies to ensure that patients with predictable degenerative diseases do issue declarations of that kind.

This case raised questions to do with the previously expressed wishes of the patient, the rights and obligations of her representative, and whether it was morally and legally acceptable for him to withdraw sustenance and allow her to die of dehydration and malnutrition. The question of the previously expressed wishes of the patient<sup>3</sup> has particular moment when, as in this case, the condition is a chronic degenerative brain disease following a predictable course. Crucial to the issue are the differing notions of what is meant by “dignity” and whether when applied to a patient’s degenerated condition perceived indignity of the condition itself (not the treatment) is relevant to decisions not to sustain life by non-burdensome means.

The public discussion drew different responses from within the Catholic tradition. The Archdiocese of Melbourne, having applied successfully to the Court to be heard as a friend of the Court, argued against withholding sustenance. The diocese argued that the treatment was not itself overly burdensome or disproportionate and that to authorise withdrawal would be to “condone hastening death by calculated omission.”<sup>4</sup> However, some well-known Catholic doctors argued in favour of the decision to withdraw. For instance, John J. Billings, MD wrote:

The valid conclusion to be made is clearly that which the woman had made many years ago<sup>5</sup> and with which all the members of the family now agree, that it would be a mercy to release her from her undignified and grave incapacity by discontinuing the tube feeding and allowing her to die.<sup>6</sup>

This paper is a multidisciplinary attempt to clarify that discussion in the hope that by doing so we can foster agreement within the Catholic tradition. The difference of opinion between respected Catholic authorities caused great distress and caused confusion about the Church’s advocacy for human life and human dignity. Many saw Dr. Billings’ intervention to be indistinguishable from advocating euthanasia for those whose condition was judged to be “undignified and [of] grave incapacity.” Others saw the Church’s intervention as an officious interference in a matter that should be left to families and physicians.<sup>7</sup>

The questions are:

1. Is it morally acceptable for a person to instruct that he or she is not to receive artificial nutrition and hydration if in the future he or she is in a persistently unresponsive state from which there is little likelihood of recovery?
2. If a patient is now incompetent, how far should that previously expressed wish of the patient not to continue with nutrition and hydration influence the

decision of the doctor or a court?

3. May or should a medical practitioner continue with the treatment in that case if the treatment itself is considered by the doctor to be not overly burdensome to the patient, the family or the community?

4. If a person has been legally appointed to represent the patient in medical matters, by the patient or by the public authority, does he or she have the moral right to refuse the initiation or continuation of artificial nutrition and hydration, which is not itself overly burdensome or disproportionate, on the grounds that the life itself is so disabled that it should not be prolonged or because the family is suffering and the patient would have refused?

In English-speaking countries the answers to these questions are greatly influenced by the emphasis placed on the principle of autonomy, which is considered to override medical decisions to sustain life on two grounds:

i) The view that a person who is no longer rationally autonomous has reached the stage of being a “narrative wreck” and continued survival is an affront to human dignity;

ii) Persons with progressive disease have the legal right to ensure in advance that should they permanently lose rational autonomy in the future they will not be provided with artificial nutrition and hydration to sustain life.

This article, which is adapted from a paper we presented at an International Congress in Rome in March, addresses these questions in the light of the Catholic Tradition, including the teaching of Pope Pius XII on this matter, the present Pope’s encyclical *Evangelium Vitae*, and the practical difficulties encountered by Catholic doctors in secularist societies. We have revised the original paper here to include discussion of John Paul II’s statement, “Life Sustaining Treatment and the Vegetative State” (see Appendix ??), which he gave to the Congress participants.

We argue that in the making of a declaration in advance, a crucial moral issue is whether the intention is that the patient not live with a certain condition. If that is the intention, then it is not a refusal that can rightly be made. The object of the refusal would be to bring about death. This is absolutely clear in *Evangelium Vitae* and in the *Declaration on Euthanasia*.

If by saying that it would be “a mercy to release her from her undignified and grave incapacity” it is meant that the intention is to bring about death by the refusal of treatment, then this is not consistent with what has been firmly taught by the Pope and by the Congregation. The question of a permissible omission does not arise if the object of the refusal is to bring about death. That is what is expressly condemned.

If on the other hand the declaration in advance expresses not a wish to die

but a refusal of a type of treatment that is itself problematic in some way then the question turns on whether there is a duty to accept that treatment and that in part is determined by its effectiveness and the difficulties involved in delivering it. This judgement is in part subjective on the part of the patient but it is also in part objective and both elements need to be satisfied.

The question is the extent to which one is obliged to undergo that treatment. This is not a question of deliberately choosing death but a question of responsibility to maintain life and the reasonable limits of that responsibility when the means to achieve it are problematic.

The problem, as we see it, in the cases such as the patient with advanced Pick's disease, is that there are usually no such difficulties once a PEG has been established. The feeding is not itself problematic and it is effective in sustaining life. The difficulty is over the fact that the life continues. The moral difficulty over feeding is that the withdrawal of feeding is based on the notion that the life should not continue and that leads to the decision that the feeding should stop. The object then of that decision is to bring about death.

Some have adopted the view that this is permissible because of the medical condition of the patient, perceived indignity of the condition and the suffering of families as the life continues to be prolonged. This is a view being adopted by some Catholic doctors and some of their theological advisers. Is it an overly secularised view? Does it challenge the Tradition in relation to respect for human dignity and the worth of every life no matter how disabled?

We argue that no one has a life that is not dignified in the relevant sense of being made as a psychosomatic unity in the image and likeness of God. We conclude that one has a duty to maintain life by means that are not in themselves disproportionately burdensome, and one may not give a direction in advance to the contrary regarding oneself.

We argue that there is a place for patients issuing declarations in advance but the moral limits need to be clarified

We address the moral issues involved for health professionals in the trend toward the use of directives issued in advance of the progress of a degenerative condition.

#### Twenty Propositions

1. *Whatever the level of disability, while ever he or she is bodily still alive, the human being remains an inherently intellectual spiritual being by virtue of being a body formed by an intellectual spiritual soul.*

Speaking in relation to the "vegetative state," Pope John Paul II has affirmed that "the intrinsic value and the personal dignity of every human



being do not change, no matter what the specific circumstances of their life. Human beings, even if they are seriously ill and impaired in the exercise of their highest functions, are and always will be human beings and will never become 'vegetables' or 'animals.' Our sisters and brothers who are in a 'vegetative state' fully preserve their dignity."<sup>8</sup>

It is worth noting in this respect that the Australian National Health and Medical Research Council has recently published a document<sup>9</sup> in which it maintains that the phrase "vegetative state" is prejudicial to the interests of patients who are in a state of unresponsiveness through illness or brain injury. The NHMRC prefers the more accurate term "post-coma unresponsiveness." Post-coma unresponsiveness (VS) which is applied to patients emerging from coma is an apparently wakeful unconscious state in which there is:

- Complete lack of responses that suggest a cognitive component;
- Preservation of sleep-wake cycles and cardio-respiratory function; and
- Partial or complete preservation of hypothalamic and brain-stem autonomic functions.

The Council of Vienne in 1311 decreed that the parts of our human nature are united together, "namely the human, passable body and the intellectual or rational soul truly of itself and essentially informing the body."

The human being is an inherently rational and spiritual being and does not have several souls—vegetable, animal and intellectual or spiritual.

*2. The term "vegetative" should not be applied to human patients, whatever their level of disability, because the term is contrary to human dignity and not a reflection of the reality that the patient has an intellectual spiritual soul.*

The Pope maintained that physicians and health workers, society and the Church have a moral duty toward these persons which they cannot shirk, without neglecting the requirements of professional deontology as well as Christian and human solidarity. "Sick people in a vegetative state, waiting to recover or for a natural end, have the right to basic health care (nutrition, hydration, hygiene, warmth, etc)."<sup>10</sup>

The probability that there is little hope for recovery, "when the vegetative state lasts longer than a year, cannot ethically justify abandoning or interrupting basic care, including food and hydration, of a patient." Death by starvation or dehydration carried out "consciously or deliberately is truly euthanasia by omission."<sup>11</sup>

The Pope recalled the "moral principle according to which even the slightest doubt of being in the presence of a person who is alive requires full respect and prohibits any action that would anticipate his or her death. The

value of the life of a man cannot be subjected to the judgement of quality expressed by other men; it is necessary to promote positive activities to counteract pressure for the suspension of food and hydration, as a means to putting an end to the life of these patients.”<sup>12</sup>

“Above all,” he added, “we must support the families” that have a patient in the vegetative state. “We cannot leave them alone with the heavy human, economic and psychological weight.” Society must promote “specific programs of assistance and rehabilitation; economic support and help at home for the family; and support structures when there are no family members able to address the problem.” In addition, he said, volunteers provide “fundamental support to help the family to escape isolation and to help them to feel a valuable part of society and not abandoned by social institutions.”

John Paul II ended by emphasizing that “in these situations spiritual and pastoral help is especially important in order to understand the deeper meaning of a seemingly desperate situation.”

The Pope held that water and food, even when administered artificially, are “a natural means of preserving life, not a medical procedure. Therefore, their use must be considered ordinary and appropriate and as such, morally obligatory.”

A feature of the Rome congress was the witness given by so many doctors and nurses engaged in the care of those who through illness or injury are no longer responsive. European doctors expressed surprise that, in Australia, doctors and nurses consider it permissible to withdraw basic care such as nutrition and hydration. We were told that in France, where it is not permissible to allow religion to influence medical practice, it is a criminal offence to withdraw food and water from a person who is in an unresponsive state, even if they have previously requested the withdrawal.

It is a sad reflection on Australia that the NHMRC document refers to the lack of doctors with experience in the long-term care of people in an unresponsive state. Yet on the corresponding European data, there should be at least 400 Australian patients in that condition. Missing in Australia would seem to be clinics that specialise in caring for people in an unresponsive state with activities designed to maintain them physically and to stimulate mental capacity.

*3. The polarisation of contemporary discussion of patients who have persistent unresponsiveness (PVS) represents a clash between*

- *modern culture, which insists on existential dignity and*
- *the Christian tradition of upholding of essential or connatural dignity.*

“Human dignity” has a philosophical and theological meaning that refers

to the worth of a human being. The International Human Rights instruments say that every member of the human family has inherent human dignity (it cannot be lost, taken away, given away, sold or exchanged) from which our equal and inalienable rights are derived. This notion of dignity is not dependant on a person's level of function or capacity: each has it simply by being a member of the human family.

But in common parlance we do refer to undignified acts (acts which are not consistent with our being rational beings) and we do refer to undignified circumstances, circumstances that are somehow demeaning to us. The philosopher Herman Spiegelberg lists the following attributes of dignity as a concept:

- being both inherent and a goal to be achieved or created and not naturally endowed;
- unassailable but able to be violated;
- independent of recognition but demanded by the disinherited;
- incapable of being lost but lost by doing acts "below human dignity";
- worthy of respect but sometimes linked with respect as in "worthy of respect and dignity."<sup>13</sup>

Much of this, Spiegelberg suggests, is explained by distinguishing between human dignity and "treating someone with dignity."<sup>14</sup> He suggests further that "human dignity" may be defined as "the worth of a person who is worth being for his own sake, regardless of his usefulness for another," but then admits that it must be more complicated than that and concludes by saying,

The search for grounds of human dignity presupposes a full-fledged philosophical anthropology, showing not only man's essential nature, its ingredients, its structure and its place in the cosmos, but also his values, rights and responsibilities.<sup>15</sup>

Human dignity has a philosophical and theological meaning within the Christian Tradition. In *Gaudium et Spes*, the Second Vatican Council taught that the divine image is present in every man and that every man is endowed with a spiritual and immortal soul.<sup>16</sup> It is in this teaching that our Tradition sources human dignity. Human dignity is inherent, it cannot be lost and is not dependent on capacity. We do not lose our human dignity because we are dependent on others or because disease robs us of the ability to reason and to communicate. Dignity, in the sense of human worth, exists in having an immortal soul, not in an individual's level of functioning. On that basis, loss of function is not itself a reason for not providing life-sustaining treatment.

In discussing the patient with advanced Pick's disease, when Dr. Billings refers to the patient's "undignified and grave incapacity" it is not clear what he means. This would seem to refer both to her condition (immobility,

incontinence of bowel and bladder, total loss of cerebral activity and of cognitive functions) and what is done to manage her condition (“the use of a hoist for showering”). However it was not claimed that she was experiencing indignity. The indignity referred to is not the way she feels but perhaps the way that she would have felt were she to be capable of being aware of her circumstances and what was being done to her as part of her care. Perhaps what is meant is that the relatives *feel* that her condition is undignified.

Are a competent person’s feelings, attitude or desire about such matters, in prospect of degenerating to such a state, a legitimate reason for her to refuse life-sustaining care for the later time? In the patient’s declaration the issue of willing her own death for that later time cannot be avoided. If her declaration is, *do not feed me then because it would keep me alive and I would not want to live in those circumstances*, then this is indistinguishable from a suicidal wish (albeit one for which we might have considerable sympathy). The intention is to bring about death by omitting that which would otherwise have been provided. Given the reason, not wanting to live with a condition that is undignified and lacking capacity, the request is intended to bring about death. The object of the request is to bring about the end of life (of a certain kind). This is to be distinguished from a request that others not undertake a measure that is disproportionate or overly burdensome where the disproportionality concerns the hardship to which they may be put to deliver that measure.

One can understand the anguish that a person may have over impending loss of function in a degenerative disease and that a person might not want to burden the lives of his or her family with his or her own self as the illness increases dependency on them. But in considering an advance declaration, it would seem that we are not free to give an instruction that is based on some other notion of human dignity that relativizes dignity to capacity and functions and declare ourselves to be worthless in a given set of circumstances. We may decide that the efforts needed to sustain us impose an undue burden on others, provided that those efforts really are burdensome, and disproportionately so. But the kindness that may motivate us to free others of their responsibility to us is misguided if it involves demanding that we be treated as less than the possessors of the inherent human dignity given to us in our creation by God in his image and likeness.

It was said that, to her family, the patient with Pick’s disease had been rendered dehumanised and depersonalised by the disease. The wife and mother that they had always cherished no longer seemed to be there.

Loss of psychological personality often happens as a result of disease, but this is not loss of personality in the sense in which it is important to a Christian,

the personality that is the result of being made in the image and likeness of God with an immortal soul. That BWV is now unable to respond, does not mean that the person has gone. The love that we are called to give is not conditional upon response, but unilateral. The love for mother or spouse is not conditional upon her response. She remains the mother that they had always cherished. While the call upon their love may be greater now because the love receives no reward, the obligation to love remains despite the grave incapacity. More than that, their supportive responses to her needs continue to be virtuous, continue to be the expression of their personalities. Her personhood remains an opportunity for them to develop in the image and likeness of God by loving her, even when she is unresponsive.

Following Christian tradition, Luke Gormally contrasts *connatural dignity* with *existential dignity*.<sup>17</sup>

*Existential* dignity is the kind of dignity a person acquires in virtue of the character of the choices he makes and which shape his life, and is dependent on a person continuing to function rationally and autonomously. Some authors refer to loss of existential dignity as “becoming a narrative wreck.”

*Essential* or *connatural* dignity is the dignity that is inherent to a human being because he or she has an intellectual spiritual soul made in the image and likeness of God, redeemed by Christ and called to communion with him. It is this notion of dignity that results in us upholding respect for human life from beginning as an embryo without evident ability to think, throughout all stages, whatever happens, and until the end of life, even though for some the end of life is preceded by a phase of lost intellectual ability.

Making an advanced declaration to refuse treatment is thus not without the moral limitation that one ought not ask others to behave in ways which are less than virtuous, to ask them to treat oneself as less than a person with inherent human dignity.

4. *A patient's level of disability or lack of existential dignity is not a reason for withdrawing treatment that is not overly burdensome and which would maintain the patient's life.*

The problem, as we see it, in the case of the patient who becomes permanently unresponsive (as happens in advanced Pick's disease) is that there are usually no such difficulties once a PEG has been established at some earlier time.

The feeding is not itself problematic and it is effective in sustaining life. The “difficulty” is over the fact that the life continues. The moral difficulty over feeding is that the withdrawal of feeding is based on the notion that the life should not continue and that leads to the decision that the feeding should

stop. This is the issue that has to be dealt with, not the issue of burdensomeness, or unreasonableness or disproportionality of the feeding. The PEG feeding is obviously none of those things, in itself, unless some complication develops with the PEG.

Questions are raised about the dignity of what is called “merely bodily life,” and with it the issue of dualism—the idea that there can be a bodily human life without a spiritual soul. In other words, are we any longer dealing with a human life in a meaningful sense? This is a discussion worth having, because there has been a medical trend toward declaring that permanent loss of consciousness (which is more certain in the case of a degenerative disease than it is in sudden trauma) is sufficient reason to declare that there is no longer a living human being, just a body. This would involve a definition of death beyond brain death and so as to include permanent loss of consciousness. Many of the ICU units that we have dealt with already practice this even though the legal definition has been loss of all functions of the brain.

If we continue to hold that a diagnosis indicating permanent loss of consciousness is not sufficient reason for declaring that death has occurred, then we are obliged to use ordinary, non-burdensome means of sustaining life, even if the fact that the life continues may itself be a burden to others and may prolong their grief. We are not permitted to withdraw treatment with the object of ending the patient’s life. The latter is the unambiguous and constant teaching of the Magisterium.

This issue goes to the heart of the nature of the human person and to the doctrinal rejection of dualism. It is our view that whole brain death can be accepted within Christian teaching, because the body is no longer an integrated whole, integration being an essential characteristic of human individuality. The brain is an essential component, through the neural and endocrine systems, of the functional relatedness of the parts of the body to the whole. Without it there is no longer communication between the parts. But that integration remains at least to some extent in a patient with lower levels of brain function even if the patient has permanently lost cortical function. Moreover, medically, philosophically and theologically we are unable to determine what consciousness is and whether it can be considered to take place exclusively within the observable functioning of the cortex. We must give the anencephalic infant the benefit of the doubt in this respect just as we must give BWV-type patients the benefit of the doubt in that respect. Sustaining a patient is an important part of palliative care. The delivery of nutrition and hydration has great significance since they are a normal part of life without which no one can survive. Their delivery is a basic way in which we show we care for and love one another.

In making a declaration in advance about nutrition and hydration, it is important not to ask others to fail to fulfil that obligation. However, such a declaration might reasonably take into account that there are circumstances in which nutrition and hydration are not warranted.

*5. There are circumstances in which nutrition and hydration are not warranted, such as*

- The patient's system is shutting down and N&H would actually hasten death or the patient cannot assimilate them;*
- The only available means of delivery would be disproportionately burdensome;*
- Death is imminent and inevitable and N&H is futile because it would not prolong life or serve to relieve distressing symptoms.*

In the case of the patient with Pick's disease, it was clear that the nutrients delivered were able to be assimilated and that the patient's system at that time was not shutting down. The problem was that the PEG feeding was successful in sustaining life. Neither was death imminent. That is to say, the patient was dying, but death was not imminent. The patient was not yet in the terminal phase of her terminal illness. The matter was brought to court precisely because she continued to live and would be likely to continue to live for a considerable time provided feeding was maintained.

Whether the treatment was disproportionately burdensome was difficult to assess. It was not argued that the patient was suffering pain or discomfort from the tube itself or that the site was excoriated and causing difficulty. The tube was already in place and had been for three years, so there was no issue about having to undertake surgery to create the facility. There was burden for the family and the carers. But the burden was more to do with the fact that she continued to survive with diminished capacity and high dependency and needed nursing care. The PEG feeding did not appear to be burdensome in itself, though not being close to the case we cannot be confident that it was not.

There was discussion about the artificial nature of PEG feeding and the fact that the mixture of nutrients used represented significant technology in its development. In a society where such resources were scarce that might have been an issue. But it was not suggested that the feeding itself caused hardship. That the feeding was artificial does not seem to have moral significance in itself. The substance being used was a substance that was also used for oral feeding.<sup>18</sup> In any case, much of what we ordinarily surround ourselves with in modern society is artificial in the sense of man-made. That does not make it unnatural in a moral sense.

Some argued that PEG feeding is not “normal.” That is certainly so. It may be that an argument could be sustained that somehow the method of feeding itself is repugnant because so abnormal. Certainly, one may be sympathetic to the view that there does come a stage in the human condition when such efforts seem to be overzealous and a denial of the reality of the human condition and of our deaths. That is certainly the case when death is imminent and inevitable. But death in this case was not imminent provided that nutrition and hydration were maintained.

A declaration by a patient facing the prospect of advancing Pick’s disease that she was not to have the surgery to have a PEG fitted, might be morally justifiable, given the significant burden and intrusiveness of the surgery and the risks. But a declaration that such feeding cease at some later point on the grounds that the patient does not now want to survive at the predictable later state of degeneration and lost function and capacity, would seem to be indistinguishable from a request to have his or her death caused by omission. To make such a request would seem to be gravely immoral.

6. *A decision to withdraw treatment or care because the patient lacks existential dignity is an omission that has as its object the death of a human being.*

In his encyclical *Evangelium Vitae*, Pope John Paul affirmed with some clarification the earlier teaching of the Congregation for the Doctrine of the Faith. He writes:

Euthanasia must be distinguished from the decision to forego so-called “aggressive medical treatment,” in other words, medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family. In such situations, when death is clearly imminent and inevitable, one can in conscience “refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.” Certainly there is a moral obligation to care for oneself and to allow oneself to be cared for, but this duty must take account of concrete circumstances. It needs to be determined whether the means of treatment available are objectively proportionate to the prospects for improvement. To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death.<sup>19</sup>

In the Catholic debate there has been a question over whether the statement, “It needs to be determined whether the means of treatment available are objectively proportionate to the prospects for improvement,” applies only in the circumstance where death is clearly imminent and inevitable. This passage in the encyclical and a similar passage in the Declaration on Euthanasia (DE) seem ambiguous in this respect.



The tradition seems clear that treatment may be withdrawn if it is itself disproportionately burdensome or simply futile. Pope Pius XII referred to the legitimacy of withdrawing ventilator support on these grounds without restricting the permission to the circumstances of imminent and inevitable death.<sup>20</sup> The earlier tradition also referred to it not being obligatory to use extraordinary means of care and this had some meaning when professional health care was outside of what could be afforded by people in ordinary circumstances. Health insurance and public schemes removed some of the meaning from that distinction. Medical care is now within the reach of most if not all people in developed economies. The Congregation (in DE) in 1980 opted instead for “the application of a medical procedure disproportionate to the results that can be expected.” But the focus is on the means, not on a judgment about the worth of the patient.

Careful thinking has also been needed in relation to the use of the word “futile.” In this case “futile” means that it would not be effective in prolonging life. Moralists have been careful to explain that this ought not be a decision based upon a judgement that *the quality of life of the patient* is futile or overly burdensome. The decision is to be a decision about the treatment itself, and not a decision about whether the patient should live or die. Disturbingly, the term “medical futility” has come to be used to describe not the effectiveness of treatment, but the level of disability of the patient. Thus W. Daniel Doty *et al.* write about “medically futile conditions” in their article in the journal *Clinical Cardiology*.<sup>21</sup> This is different from referring to medically futile treatments.

*7. Medical assistance to prolong life may be obligatory, especially where the medical assistance to care in fact reduces the burden of care.*

This is certainly the case in relation to feeding by Percutaneous Endoscopic Gastrostomy (PEG).

PEGs are most often put in place because they are a much cheaper, much less labour intensive form of feeding than hand feeding a patient who cannot manage to feed himself or herself, particularly if the patient is slow to swallow or has difficulty swallowing.

The cost of provisioning and maintaining a PEG is less than 30% of the cost of paying an aide to hand.

*8. The emphasis on withdrawing artificial nutrition and hydration (ANH) in this debate is not because ANH is disproportionately burdensome or because it is ineffective.*

Although some methods of artificial feeding may be overly burdensome (total parental nutrition is expensive because of the pathology required and

a naso-gastric tube may be uncomfortable for a conscious patient), in reality in an unconscious patient or if a PEG is in place and uncomplicated, feeding is not overly burdensome.

*9. The issue of feeding people who are persistently unresponsive (PVS) arises because there is a view that they should not survive in a state lacking existential dignity, not because there is likely to be anything wrong with feeding them or with the the method of feeding.*

The problem for those who think that a persistently unresponsive patient should be dead is that feeding is effective in maintaining life. The burden is not the feeding but the continued existence.

*10. There are several legitimate reasons why a patient may make an advanced directive or "living will," such as:*

- *To save one's family from the anguish of making the decisions;*
- *To ensure that future treatment (in a culture of death) is morally acceptable and consistent with respect for human life and dignity;*
- *To prevent the over-use of limited health resources;*
- *To prevent zealous over-treatment.*

A person with a chronic, progressive illness, or because of advanced age, may expect to lose the capacity to make and express competent decisions about medical treatment. A declaration in advance may be to request or to refuse various treatment options.

The difficulty with a declaration in advance is that it only comes into effect when the patient is no longer competent. In making such a declaration one is addressing duties and obligations of others. It would be wrong to make a declaration that requested of them a moral evil or that established a moral obligation that was too onerous.

An advanced declaration thus needs to take into account the agent who is to carry out the wish of the patient, the agent's circumstances, the health care team and an objective assessment of the moral goodness of what is requested.

In that respect an advanced declaration ought not be a request for euthanasia defined in our tradition as an action or an omission which of itself and/or by intention causes death.<sup>22</sup>

*11. The trend toward declarations in advance also has a negative aspect in that it reflects a lack of acceptance and desire to control illness and dying.*

Pope John Paul II wrote in *Evangelium Vitae*: "When he denies or neglects his fundamental relationship to God, man thinks he is his own rule and measure, with the right to demand that society should guarantee him the ways and

means of deciding what to do with his life in full and complete autonomy.”<sup>23</sup>

*12. The encouragement of advance directives by doctors and health institutions has a sinister aspect because it reduces the legal and ethical responsibility of doctors and health care institutions for their actions.*

Our experience in Australia is that patients are encouraged to take responsibility for decisions and thus provide a legal or ethical cover for decisions by a doctor, or health institution, that would otherwise be illegal or unethical.

*13. Since making an advanced declaration involves addressing duties and obligations of others, it would be wrong to make a declaration that requested of them a moral evil, including immoral neglect, or established a moral obligation that was too onerous.*

The crucial issue in making an advanced declaration is the matter of what it is that one is directly willing. It is legitimate not to want to impose a burden on others for one's continued existence, but it is not legitimate to will that they should be relieved of that burden by one's life being ended by the withdrawal of life-sustaining care which is not itself excessively or disproportionately burdensome.

An advance declaration to refuse life-sustaining care, such as artificial nutrition and hydration, is a decision to end one's life. It is suicide. As Pope John Paul II held,<sup>24</sup> “Water and food, even when administered artificially, are “a natural means of preserving life, not a medical procedure. Therefore, their use must be considered ordinary and appropriate and as such, morally obligatory.”

Death by starvation or dehydration carried out “consciously or deliberately is truly euthanasia by omission.”<sup>25</sup>

It would be wrong to issue a declaration to refuse care in order that one's life should be ended as a means to preventing one's continued life being a burden to others. The object of the declaration would be evil, even if the intended consequence is good.

The object of the act of willing is in fact a freely chosen kind of behaviour. To the extent that it is in conformity with the order of reason, it is the cause of the goodness of the will; it perfects us morally, and disposes us to recognize our ultimate end in the perfect good, primordial love. By the object of a given moral act, then, one cannot mean a process or an event of the merely physical order, to be assessed on the basis of its ability to bring about a given state of affairs in the outside world. Rather, that object is the proximate end of a deliberate decision which determines the act of willing on the part of the acting person.<sup>26</sup>

An object of an act is good when it has as its aim the true good of the

person in view of his ultimate end.<sup>27</sup> The intended consequences must also be good.<sup>28</sup>

In other words if either the direct object (in this case death by starvation and dehydration) is evil or the intended consequence is evil, then the act is evil. The advanced declaration to refuse food and water may have a good intended consequence (relieving others of a burden), but its immediate object (death by starvation and dehydration) is evil. Willing one's own death is an evil, because taking that decision to oneself is not capable of being ordered to one's ultimate end defined in terms of one's relationship with God and of the goodness of the life that he has given to us.

14. *"God alone is the Lord of Life from its beginning until its end, no one can under any circumstances claim for himself the right directly to destroy an innocent human being" (JP II, EV n. 53; CDF Donum Vitae; Dt 32:39).*

As it is expressed in the Catholic *Catechism*, suicide contradicts the natural inclination of the human being to preserve and perpetuate life. It is gravely contrary to the just love of self. It likewise offends love of neighbour because it unjustly breaks the ties of solidarity with family, nation, and other human societies to which we continue to have obligations. Suicide is contrary to love for the living God.

15. *To be valid an advanced declaration needs to have*
- *been made competently, freely and informedly,*
  - *taken into account the actual circumstances of the patient at the time when it is to be applied, the agent who is to carry out the wish of the patient, the agent's circumstances and those of the carers,*
  - *an object and intended consequences that are not morally evil.*

To intervene medically, the health care professional should have the express or tacit consent of the patient.<sup>29</sup> Pope Pius XII expressed this very clearly in 1957: "[The doctor] does not have a separate and independent right in relation to the patient. In general, he can act only if the patient explicitly or implicitly (directly or indirectly) authorizes him."<sup>30</sup>

Without such authorization he gives himself an arbitrary power. "The patient cannot be the object of decisions which he will not make, or, if he is not able to do so, which he could not approve. The "person," principally responsible for his own life, should be the centre of any assisting intervention: others are there to help him, not to replace him."<sup>31</sup>

Pope John Paul II described the patient as "the responsible person, who should be called upon to share in the improvement of his health and in becoming cured. He should be given the opportunity of personally choosing,

and not be made to submit to the decisions and choices of others.”<sup>32</sup>

The process of obtaining permission, or informed consent, as it is usually termed, is often complex as there are several elements that are considered important, such as whether the patient:

- Possesses all the information that would be likely to affect his or her decision to consent to intervention;
- Is free from any form of coercion that would affect the decision; and
- Comprehends the information and is able to relate the decision to the information.

Thus the issue turns on whether the patient is informed, free and competent in relation to the decision to consent.

In North America a particular notion of “informed consent” is used in which a consenting person who lacks relevant information may be considered not to have consented at all. In some other jurisdictions, the notion of informed consent is separated into two distinct notions:

- The duty of disclosure which is an aspect of the duty of reasonable care (failure to comply may be considered to be professional negligence);
- The matter of trespass to the person if a procedure is done without consent.

Pope John Paul II asserts that the patient should be given a precise idea of his illness and the therapeutic possibilities, with the risks, the problems and the consequences that they entail so that he can make a choice with full awareness and freedom.<sup>33</sup>

These matters were analysed in great detail by Pope Pius XII. In relation to the doctor’s right and duties, Pope Pius XII taught:

The rights and duties of the doctor are correlative to those of the patient. The doctor, in fact, has no separate or independent right where the patient is concerned. In general he can take action only if the patient explicitly or implicitly, directly or indirectly gives him permission.<sup>34</sup>

The previously expressed wishes of a patient may thus be taken into account, bearing in mind the difficulties of issuing directions in advance given the unpredictability of the progress of an illness, and the inability of young persons, for instance, to imagine what life would be like at a stage of old age and infirmity. (Teenagers think incontinence would be intolerable; older people learn to live with it.)<sup>35</sup>

However, there are limitations on what the patient may direct which were addressed earlier. Obviously the patient cannot create overriding obligations for measures that cannot be delivered without difficulty for others or which compromise their moral or professional integrity. The question is whether the patient’s refusal of treatment or withdrawal of permission, however immoral, would be overriding.

An emergent issue is the extent to which doctors who uphold traditional values in relation to human life find themselves confronted by circumstances in which patients refuse treatment, even quite ordinary/non-burdensome care. Such refusals may also be accompanied by a demand for the cooperation of the doctor in managing symptoms that are the result of that neglect so that they can die comfortably.

In the care of the dying (and many other areas) a gap is emerging in the culture of death between traditional norms of medical practice and the new-found notion that the patient's autonomous choice validates a procedure that might otherwise have been considered unethical. The patient's informed choice within the consent process has several facets:

- Permission,
- Authorization or validation, or
- Demand

In the first instance, consent means what it means when a doctor offers what would be regarded by the profession as reasonable care within the ethical standards of the profession, but requires the patient's permission before proceeding.

In the second instance, the *reasonable care* applies only to the competent delivery of the service. The consent of the patient gives ethical authority or validation *and that is all that is needed* to meet the ethical standards. There is no objective ethical standard. Often, the defence of doctors practicing reproductive technology excesses, or dubious procedures, such as sexual reassignment surgery, has been simply that the patients consented. The patient's consent puts aside any other moral qualms.

In the third instance, the choice of the patient entitles the patient to expect the service from the professional whatever the latter's ethical reservations. This is becoming increasingly the case in relation to post-coital intervention, for instance. In the care of the dying, it is becoming so that a doctor who refused to provide a fatal overdose may be regarded as negligent. Most legislative proposals for euthanasia have made allowance for conscientious objection, but not all. Many of those that do allow for conscientious objection qualify it by insisting that such an objection would require that the doctor refer the patient to someone who would provide the service. There is little scope for allowing a doctor to refuse to cooperate in the evil of making such a referral.

In this discussion it is important to recognize what the confrontation is between a traditional Hippocratic Ethic and liberal bioethics. This is a confrontation with a new moralism, a moralism that asserts autonomy as the supreme value.

. . . although Mill and some other supporters of the liberal ideal purport to justify it (the ideal of autonomy) in utilitarian terms—the principle of individual liberty leads to the most beneficial social consequences—there is no essential link between the liberal ideal and the theory of utilitarianism. In fact, personal autonomy is an ‘absolute’ value or intrinsic good regardless of any consequences it may have, and it is for that reason that a utilitarian justification is inadequate.<sup>36</sup>

. . . . autonomy, the capacity for self-determination, is also valuable in itself in the sense that, even though *what* I choose (the content of my act) is objectively bad, my choosing it is still good in that it is a free and autonomous act as opposed to one that is coerced. If we contrast two acts: (a) one that is freely chosen but objectively wrong, and (b) one that is coerced and not freely chosen, but which is also objectively good, the liberal will say that the first act is more valuable than the second.<sup>37</sup>

The idea of autonomy is a blindingly obvious one. It simply means that if I am to act in an ethical or moral way I must choose for myself what I am going to do. I may of course take advice from others and I may be subject to persuasion and pressure from external sources, but when the chips are down I must decide for myself. Only then is what I have done imputable to me so that it is *my* act, and only then am I responsible for it and praiseworthy or blameworthy for it.<sup>38</sup>

. . . the liberal society claims that, at least ideally, members of society are required only to agree that personal liberty or autonomy is the supreme value.<sup>39</sup>

On analysis, one can identify three main liberal propositions:

a) Autonomy is the basis of human dignity. On this account you possess dignity in virtue of your present autonomy, your future autonomy (in the case of infants), or your past autonomy (in the case of senile elderly). Thus human beings who never possess autonomy lack human dignity, though there still may be morally weighty reasons for protecting and caring for them. In these ways autonomy is the basic moral category. This position has two variants. The first accords equal dignity to everyone who possesses or has possessed a threshold level of dignity. The second says the greater the level of autonomy of an individual, the greater the human dignity.

b) Autonomy is the sole intrinsic good by which the quality of life (as distinct from the extent to which we esteem persons, and as distinct from the intrinsic value of a person’s life) is to be assessed—everything else, such as health and education, is relevant via its effect on autonomy.

c) Considerations of the autonomy of those directly involved in the individual case always morally override all other considerations in deciding what ought to be done.

Gerald Dworkin comments:

There is an intellectual error that threatens to arise whenever autonomy has been defended as crucial or fundamental: This is that the notion is elevated to a higher status than it deserves. Autonomy *is* important, but so is the capacity for sympathetic identification with others, or the capacity to reason prudentially, or the virtue of

integrity. Similarly, although it is important to respect the autonomy of others, it is also important to respect their welfare, or their liberty, or their rationality. Theories that base everything on any single aspect of human personality, on any one of a number of values, always tend toward the intellectually imperialistic. One way in which this is done is by assimilating other concepts to that of autonomy.<sup>40</sup>

In defence of authority (such as medical authority), Dworkin writes:

... We lack time, knowledge, training, skill. In addition there is necessary and useful division of labor. It is more efficient for each of us to specialise in a few areas of competence and be able to draw, when we need it, upon the resources and expertise of others. Knowledge is socially stored and there are evolutionary advantages for a species that does not require each individual member to acquire and retain the knowledge needed for survival and reproduction. It may also be true that our reliance upon authority assumes that somewhere in the chain of authority, someone has engaged in (weak or strong) checking.<sup>41</sup>

A crucial matter in this debate is the notion of professional integrity and the ideal of joining a profession in order to develop and apply one's knowledge and skills in a way that serves the needs of another. Being a health professional means being committed to caring for those who are sick, preventing ill-health. Those are objective goals and they dignify the profession.

Most theories based on autonomy do not give validity to choice regardless of what is chosen. Many autonomy idealists appeal to various notions of *rational* autonomy. But the more sophisticated such theories become, the further removed they are from mere choice and the more they import notions of reasoned choice that applies standards other than mere choice. In other words, a kind of natural law develops that imposes objectively rational criteria.

One issue that is confounding for autonomy idealists is the fact that people can make autonomous choices that harm autonomy, such as suicide<sup>42</sup> or drug-taking. If autonomy were a moral trump, then in order to protect autonomy, one would be required to prevent voluntary suicide that ends an autonomous life or prevent the abuse of drugs that diminish rational function or which are addictive.<sup>43</sup>

One must distinguish between respecting a *person* because he or she *is autonomous* (has the ontological status of being a chooser), or more particularly rationally autonomous (a rational chooser), on the one hand, and, on the other, respecting a person's *choices* in relation to self-regarding matters as what is morally right for him or her—autonomy as a *moral trump*.

The first is the position taken by Aristotle and Aquinas in relation to man, the rational animal, who possesses free will. Because a man is the kind of being he is, he warrants respect for his worth and dignity. Precisely because we value him, we are not prepared to kill him, even if he wishes it.



The withdrawal of ordinary/non-burdensome care, which directly results in the death of the patient, would seem to be an omission that has as its object the deliberate ending of life and would not be permissible. The problem for the doctor is whether or not he or she knows the circumstances in which the declaration was made and the patient's reasons for making the declaration, and the extent to which the doctor can accept that earlier decision as possibly being within legitimate moral bounds.

In practice we have advised doctors to consider that there is usually a range of options that fall within what may be considered reasonable medical care. The range may vary from aggressive medicine at one end to conservative medicine at the other. What is looked for in a declaration made in advance is what the patient would want within that range of reasonable care. While the patient's wishes are limited by what is objectively acceptable, the patient makes a subjective decision within the range of what is objectively acceptable. This permits the patient to apply his or her own moral judgment about proportionality in relation to factors such as the burden to others (family, carers or society) of the treatment options and the burden to him or herself and the likely effectiveness of the treatment.

Advance declarations are always problematic if the circumstances are not known. There are also complications of patient declarations that are ambiguous, not independently witnessed, ill-informed, old or not very specific.

There is a need to identify whether:

- a) The person was fully informed and that the later circumstances conform in relevant ways to the situation that he or she envisaged;
- b) The person was acting freely and was not being coerced or pressured in any way to issue the declaration;
- c) The person comprehended the impact of what he or she was declaring;
- d) There is no reason to think that the declaration was made on immoral grounds, such as an intent to suicide.

Pope John Paul II writes:

To concur with the intention of another person to commit suicide and to help in carrying it out through so-called "assisted suicide" means to cooperate in, and at times to be the actual perpetrator of, an injustice which can never be excused, even if it is requested. In a remarkably relevant passage Saint Augustine writes that "it is never licit to kill another: even if he should wish it, indeed if he request it because, hanging between life and death, he begs for help in freeing the soul struggling against the bonds of the body and longing to be released; nor is it licit even when a sick person is no longer able to live." Even when not motivated by a selfish refusal to be burdened with the life of someone who is suffering, euthanasia must be called a false mercy, and indeed a disturbing "perversion" of mercy. True "compassion" leads to

sharing another's pain; it does not kill the person whose suffering we cannot bear. Moreover, the act of euthanasia appears all the more perverse if it is carried out by those, like relatives, who are supposed to treat a family member with patience and love, or by those, such as doctors, who by virtue of their specific profession are supposed to care for the sick person even in the most painful terminal stages."<sup>44</sup>

*16. An advanced directive which has an evil object (e.g., bringing about the patient's own death by neglect of means that are not overly burdensome) does not provide a moral justification for neglecting a patient to death.*

It is worth noting that most Western jurisdictions have removed the offence of suicide for practical reasons, but have:

- retained the offence of assisting suicide;
- retained the right of others (and the duty of those with a duty of care) to intervene with reasonable force to prevent a person from committing suicide if there is a reasonable belief that suicide is being attempted.

Presumably a doctor who had reasonable grounds for believing that an advanced directive was suicidal could continue to give life-maintaining treatment on those grounds. However, much may depend on the statutory provisions in relation to advanced declarations.

*17. Patient directives refusing treatment do, to an extent, remove the doctor from the formal decision-making and an assessment of the morality of the act of the doctor in complying would depend, in part, on the nature of the doctor's cooperation and whether the doctor was either formally part of the decision or was so cooperating that his actions were an endorsement of the patient's decision.*

The problem for Catholic and pro-life doctors is that more and more Courts and Parliaments are giving an overriding significance to the declaration of a patient made in advance. Because such declarations are in reality dependent upon knowledge of the circumstances in which they are made, some flexibility may remain for doctors to interpret their application in a given instance. However, that flexibility may not be available if the interpretation of the patient's wishes is in the hands of a Court or in the hands of an appointed representative who has been given that authority.

In those circumstances, the role of the doctor as decision-maker has been displaced. The matter then becomes a question of what the doctor is directed to do or not do, and whether the doctor's diminished role as a decision-maker is formal cooperation in the immoral project or is so diminished that he or she is no longer formally part of the decision and hence only materially cooperates. If the latter is the case, then it may be that the doctor should withdraw, but it may also be the case that there is a morally acceptable role

to perform as part of the team caring for the patient, which does not compromise the doctor's moral integrity. The matter would need to be determined theologically according to an assessment of the principles that govern legitimate cooperation in moral evil.

18. *Some acts that would be morally excluded for the doctor would include:*

- *advocating the use of advanced declarations to refuse treatment or care that was not itself disproportionately burdensome;*
- *causing moral scandal by activity that implied that such uses of advanced declarations were morally acceptable; and*
- *publicly supporting refusals of treatment where the object of the refusal was to bring about death.*

The issue in each of these cases is the doctor's witness to respect for human life made especially significant by his or her professional vocation.

19. *A legally appointed representative, with a power of attorney from the patient or a court appointment as a guardian, has the same moral authority as the patient in relation to medical treatment.*

The appointment of a person with enduring power of attorney for medical treatment or similar legal provision places that person in a position of acting with the authority of the patient.

Pius XII addressed the question of the representation of an incompetent patient in the following way:

What We say here must be extended to the legal representation of the person incapable of caring for himself and his affairs: children below the age of reason, the feeble-minded and the insane. These legal representatives authorized by private decision or by public authority, have no other rights over the body and life of those they represent than those people would have themselves if they were capable. And they have those rights to the same extent. They cannot, therefore, give the doctor permission to dispose of them outside of those limits.<sup>45</sup>

Very clearly, in this statement Pope Pius XII envisaged both that which we would now call "*an enduring power of attorney (medical)*" (private decision) appointed by the patient while competent, and that which we would call "*a guardian*" appointed by the State (public authority). It would seem clear therefore that the concepts of enduring power of attorney and State appointed guardians with the authority to make decisions concerning the medical treatment of a patient are morally legitimate options in the moral traditions of the Church.

The text also indicates that Pope Pius XII taught that the representatives of the patient have the same rights over the body and life of the patient as the patient would have had over him or herself. In the earlier section we

addressed the moral obligations of the patient in relation to the refusal of artificial nutrition and hydration, which is not itself overly burdensome or disproportionate, on the grounds that the life itself is so disabled that it should not be prolonged or because the family is suffering and the patient would have refused. Evidently the representative of a patient has no greater right to refuse treatment.

Addressing himself to the proper role of the unconscious patient's family, Pope Pius XII observes: "The rights and duties of the family depend on the presumed will of the unconscious patient, if he is of age and *sui juris*."<sup>46</sup>

In relation to the family's duty to provision care by the family he wrote: "Where the proper and independent duty of the family is concerned, they are usually bound to use only ordinary means."<sup>47</sup>

Pope John Paul II in the sections to which we referred in our earlier discussion has of course explained what is meant by ordinary means more fully in terms of proportionality and burdensomeness by the Congregation.

The above teaching of Pope Pius XII about patient representation was referred to by the Congregation for the Doctrine of the Faith in 1980 in the *Declaration on Euthanasia*, as retaining its full force. However in 1995, a major difference emerged in the *Charter for Health Care Workers*.<sup>48</sup>

73. With regard to *presumed consent*, a distinction must be made between the patient who is in a condition to know and will know, and one who is not.

In the former, consent cannot be presumed: it must be clear and explicit.

In the latter case, however, the health care worker can, and in extreme situations must, presume the consent to therapeutic interventions, which from his knowledge and in conscience he thinks should be made. If there is a temporary loss of knowing and willing, the health care worker can act in virtue of the *principle of therapeutic trust*, that is the original confidence with which the patient entrusted himself to the health care worker. Should there be a permanent loss of knowing and willing, the health care worker can act in virtue of the *principle of responsibility for health care*, which obliges the health care worker to assume responsibility for the patient's health.

74. With regard to the relatives, they should be informed about ordinary interventions, and involved in the decision making when there is question of extraordinary and optional interventions.

There is no scope in the Pontifical Council's document for health care decision-making by those appointed by the patient or by the State. According to the Council, the authority for health care decision-making, when the patient is incompetent, vests in the health care worker in virtue of the *principle of responsibility for health care*. The family are to be "informed and involved," but not ultimately responsible. There is no option here of the responsibility having been exercised by the patient in advance or having been entrusted by the patient or a legal process to a representative.

This places the Pontifical Council seemingly at odds with the law in Western democracies. The Council has also not taken into account the matters addressed in relation to patient representation by Pope Pius XII.

The Pontifical Council places immense confidence in health care workers in this instance, assuming the application of distinctions such as ordinary and extraordinary care and a notion of a moral duty to provide care that distinguishes between what is obligatory and what is morally optional. These may be very large assumptions to make about the health professions in a *culture of death*.

The Council also gives no advice about what precisely the role of the representative is and what the health professional's obligations are when there is a person who is a legally appointed representative, such as a person holding a power of attorney for medical treatment or a person appointed to be a guardian.

In recent times, most Western jurisdictions have attempted to qualify the powers of a patient's representative in relation to medical treatment, inserting *patient's best interest* clauses and reference to the *patient's previously expressed wishes*.

The inclusion of clauses of that nature give the health professional and other concerned persons the opportunity to question the adequacy of the representation and to seek to have the representation reviewed. Where the representative seems to be acting contrary to the patient's interests, possibly acting for motives that are indifferent or not well-intentioned towards the patient, then we would argue that health professionals have an obligation to seek that review.

We live in different times from Pope Pius XII, and we live with structures that seem not to have been addressed by the Pontifical Council. In relation to Pius XII's teachings, it does now seem necessary to qualify the role of representatives. In relation to the Pontifical Council, we cannot ignore the reality that the structures for representation in relation to medical treatment decisions exist and we need principles to guide health professionals in relation to the role of the representatives.

This is particularly the case in the culture of death where the trend is for "quality of life" assessments of care to threaten the survival of the disabled and the incompetent.

20. *The authority of the legal representatives of patients is qualified and they may not make choices that would have been immoral for the patient to have made.*

A doctor should be permitted to override a representative who refuses

treatment that would maintain life and is not overly burdensome. This right ought to be protected in an emergency so that the doctor can initiate treatments that are not overly burdensome or disproportionate to protect life. In the event that there is a problem with a refusal of care that is not overly or disproportionately burdensome, such as artificial feeding, then there needs to be a mechanism, such as an appeal to a court or tribunal, by which a doctor can challenge the nature of the representation. It is important that where representation has a legal status there is the opportunity for a review of the representation upon request. It is also important that representatives not have an unfettered right to refuse treatment in a way that would neglect the fundamental obligation to use means of care that are not disproportionately burdensome.

### NOTES

1. This assessment was subject to dispute in the court proceedings and no finding was made.
2. John J. Billings MD, "COMMENT: Allowing nature to take its course is not euthanasia" *Newsweekly*, 3 May 2003.
3. Note that the court said that there was no admissible evidence of any express wishes of the patient and that there are good reasons to doubt the family's later recollections and surmises.
4. Bishop Anthony Fisher OP, "Death by little steps" *Kairos*, Vol. 14 No. 10, 15 June 2003
5. Note that there was a lack of evidence of her earlier conclusion.
6. John J. Billings MD, *op. cit.*
7. A reason given by Dr. Warwick Neville (Australian Catholic Bishops Conference) for the Church's intervention was to protect staff in Catholic health and aged care facilities from acting against their conscience and/or Church teaching in relation to the provision of nutrition and hydration etc. in the event that relatives of a patient in their care sought and obtained an order from a tribunal or a court ordering the cessation of treatment or care. Thus there was a strong religious liberty dimension in the litigation. [Correspondence 5/1/04].
8. Pope John Paul II, Address to Participants in the International Congress on "Life Sustaining Treatments and the Vegetative State," March 17-20, 2004, Rome.
9. Australian Health Ethics Committee, *Post-coma Unresponsiveness (Vegetative State): A Clinical Framework for Diagnosis: An Information Paper*, October 2003, Canberra, Australia: National Health and Medical Research Council.
10. Pope John Paul II, *op. cit.*
11. *Ibid.*
12. *Ibid.*
13. Spiegelberg, Herman, "Human Dignity: A Challenge" in *Human Dignity: This Century and the Next*, edited by Rubin Gotesky and Ervin Laszlo; Gordon and Breach New York 1970 p. 44.
14. *Ibid.* p. 58.
15. *Ibid.* p. 61.
16. Second Vatican Council, *Gaudium et Spes*, December 7th, 1965, n. 14, 22, 24.
17. Luke Gormally email correspondence to Dr. Nicholas Tonti-Filippini, 30/12/03.
18. "Osmolite is also appropriate as an oral feed for patients with altered taste perception." 2002 MIMS Annual, Twenty-sixth Edition, June 2002, 19-1346.
19. Pope John Paul II, *Evangelium Vitae*. Encyclical addressed to the Bishops, Priests and Deacons, Men and Women religious, lay faithful and all People of Good Will on the Value and Inviolability of Human Life, 25th May 2003, n. 65.
20. Pope Pius XII, "The Prolongation of Life": an address to an International Congress of Anaesthesiologists, November 24, 1957, in *AAS*, 49 (1957) p. 1031.
21. W. Daniel Doty and Robert M. Walker, "Medical Futility," *Clinical Cardiology*, Vol. 23 (Suppl. II) 2000.

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22. Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, 1980, repeated in the *Catechism of the Catholic Church* and again in the encyclical, *Evangelium Vitae*, but with a significant change.
23. Pope John Paul II, *Evangelium Vitae*, n. 64.
24. Statement, March 20 2004, *ibid.*
25. *Ibid.*
26. Pope John Paul II, *Veritatis Splendor*, n. 78.
27. *Veritatis Splendor* n. 82.
28. *Ibid.* n. 79.
29. Pontifical Council for Pastoral Care to Health Care Workers, *Charter for Health Care Workers*, 1995, n.72.
30. Pius XII, "The Prolongation of Life," Nov. 24, 1957, in AAS, Vol. 49 (1957) p. 1031.
31. Pont. Council Cor Unum, "Some Ethical Questions Relating to the Gravely Ill and the Dying," July 27, 1981, in *Enchiridion Vaticanum 7, Documenti ufficiali della Santa Sede 1980-1981*. EDB, Bologna, 1985, p. 1137, n. 2.1.2.
32. John Paul II, "To the World Congress of Catholic Doctors," Oct. 3, 1982, in *Insegnamenti*, V/3, p. 673, n. 4.
33. John Paul II, "To the participants at two congresses on medicine and surgery," Oct. 27, 1980, in *Insegnamenti*, III/2, 1008-1009, n. 5.
34. Pope Pius XII, "The Prolongation of Life," Nov. 24, 1957, in AAS, Vol. 49, p. 1031.
35. We are grateful to Bishop Anthony Fisher, OP for the example.
36. Charlesworth, Max, *Bioethics in a Liberal Society*, Cambridge University Press, 1993, p. 7.
37. *Ibid.* p. 13.
38. *Ibid.* p. 14.
39. *Ibid.* p. 18.
40. Dworkin, Gerald, *The Theory and Practice of Autonomy*, Cambridge University Press, 1988, p. 32.
41. *Ibid.* 45-6.
42. Immanuel Kant is often cited as the father of autonomy idealism. But Kant opposed suicide because it destroyed an autonomous individual and in his own painful terminal illness would forego pain relief in order to maintain lucidity. "Firstly, under the head of necessary duty to oneself: He who contemplates suicide should ask himself whether his action can be consistent with the idea of humanity as an end in itself. If he destroys himself in order to escape from painful circumstances, he uses a person merely as a means to maintain a tolerable condition up to the end of life. But a man is not a thing, that is to say, something that which can be used merely as means, but must in all his actions be always considered as an end in himself. I cannot, therefore, dispose in any way of a man in my own person so as to mutilate him, to damage or kill him. (It belongs to ethics proper to define this principle more precisely, so as to avoid all misunderstanding, e.g., as to the amputation of the limbs in order to preserve myself, as to exposing my life to danger with a view to preserve it, etc. This question is therefore omitted here.)" Immanuel Kant's *Fundamental Principles of the Metaphysic of Morals* as translated by Thomas Kingsmill Abbott, 1965.
43. Also confronting for autonomy idealists who see themselves as libertarians is that the consumer generation thinks of "quality of life" not necessarily as the most autonomous life but also in terms of comfort, pleasurable experience and mobility. Their ideas are far removed from the stringent notion of the ideal character espoused by Kant or Locke. These "fathers of liberalism" are not the fathers of the contemporary permissive society.
44. *Evangelium Vitae*, n. 66.
45. Pope Pius XII, "Address to 1st International Congress on Histopathology of the Nervous System," Sept. 14, 1952.
46. Pope Pius XII, "The Prolongation of Life," Nov. 24, 1957, AAS, Vol. 49, p. 1031.
47. *Ibid.*
48. Pontifical Council for Pastoral Care to Health Care Workers, *Charter for Health Care Workers*, 1995.

## APPENDIX A

[Pope John Paul II delivered the following address at an International Congress, sponsored by the Pontifical Academy for Life and the International Catholic Federation of Medical Associations, in Rome, March 20, 2004.]

### **Address of John Paul II to the Participants in the International Congress on “Life Sustaining Treatments and the Vegetative State: Scientific Advances and Ethical Dilemmas”**

*Pope John Paul II*

Distinguished Ladies and Gentlemen,

1. I cordially greet all of you who took part in the international congress “Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas.” I wish to extend a special greeting to Bishop Elio Sgreccia, Vice President of the Pontifical Academy for Life, and to Professor Gian Luigi Gigli, President of the International Federation of Catholic Medical Associations and selfless champion of the fundamental value of life, who has kindly expressed your shared feelings.

This important congress, organized jointly by the Pontifical Academy for Life and the International Federation of Catholic Medical Associations, is dealing with a very significant issue: *the clinical condition called the “vegetative state.”* The complex scientific, ethical, social and pastoral implications of such a condition require in-depth reflections and a fruitful interdisciplinary dialogue, as evidenced by the intense and carefully structured program of your work sessions.

2. With deep esteem and sincere hope, the Church encourages the efforts of men and women of science who, sometimes at great sacrifice, daily dedicate their task of study and research to the improvement of the diagnostic, therapeutic, prognostic and rehabilitative possibilities confronting those patients who rely completely on those who care for and assist them. The person in a vegetative state, in fact, shows no evident sign of self-awareness or of awareness of the environment, and seems unable to interact with others or to react to specific stimuli.

Scientists and researchers realize that one must, first of all, arrive at a correct diagnosis, which usually requires prolonged and careful observation in specialized centers, given also the high number of diagnostic errors reported in the literature. Moreover, not a few of these persons, with appropriate treatment and with specific rehabilitation programs, have been able to emerge from a vegetative state. On the contrary, many others unfortunately remain prisoners of their condition even for long stretches of time and without needing technological support.



In particular, the term *permanent vegetative state* has been coined to indicate the condition of those patients whose “vegetative state” continues for over a year. Actually, there is no different diagnosis that corresponds to such a definition, but only a conventional prognostic judgment, relative to the fact that the recovery of patients, statistically speaking, is ever more difficult as the condition of vegetative state is prolonged in time. However, we must neither forget nor underestimate that there are well-documented cases of at least partial recovery even after many years; we can thus state that medical science, up until now, is still unable to predict with certainty who among patients in this condition will recover and who will not.

3. Faced with patients in similar clinical conditions, there are some who cast doubt on the persistence of the “human quality” itself, almost as if the adjective “vegetative” (whose use is now solidly established), which symbolically describes a clinical state, could or should be instead applied to the sick as such, actually demeaning their value and personal dignity. In this sense, it must be noted that this term, even when confined to the clinical context, is certainly not the most felicitous when applied to human beings.

In opposition to such trends of thought, I feel the duty to reaffirm strongly that the intrinsic value and personal dignity of every human being do not change, no matter what the concrete circumstances of his or her life. *A man, even if seriously ill or disabled in the exercise of his highest functions, is and always will be a man, and he will never become a “vegetable” or an “animal.”*

Even our brothers and sisters who find themselves in the clinical condition of a “vegetative state” retain their human dignity in all its fullness. The loving gaze of God the Father continues to fall upon them, acknowledging them as his sons and daughters, especially in need of help.

4. Medical doctors and health-care personnel, society and the Church have moral duties toward these persons from which they cannot exempt themselves without lessening the demands both of professional ethics and human and Christian solidarity.

The sick person in a vegetative state, awaiting recovery or a natural end, still has the right to basic health care (nutrition, hydration, cleanliness, warmth, etc.), and to the prevention of complications related to his confinement to bed. He also has the right to appropriate rehabilitative care and to be monitored for clinical signs of eventual recovery.

I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*. Its use, furthermore, should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.

The obligation to provide the “normal care due to the sick in such cases” (Congregation for the Doctrine of the Faith, *Iura et Bona*, p. IV) includes, in fact, the

use of nutrition and hydration (cf. Pontifical Council “Cor Unum,” *Dans le Cadre*, 2, 4, 4; Pontifical Council for Pastoral Assistance to Health Care Workers, *Charter of Health Care Workers*, No. 120). The evaluation of probabilities, founded on waning hopes for recovery when the vegetative state is prolonged beyond a year, cannot ethically justify the cessation or interruption of *minimal care* for the patient, including nutrition and hydration. Death by starvation or dehydration is, in fact, the only possible outcome as a result of their withdrawal. In this sense it ends up becoming, if done knowingly and willingly, true and proper euthanasia by omission.

In this regard, I recall what I wrote in the encyclical *Evangelium Vitae*, making it clear that “by *euthanasia in the true and proper sense* must be understood an action or omission which by its very nature and intention brings about death, with the purpose of eliminating all pain”; such an act is always “a *serious violation of the law of God*, since it is the deliberate and morally unacceptable killing of a human person” (No. 65).

Besides, the moral principle is well known, according to which even the simple doubt of being in the presence of a living person already imposes the obligation of full respect and of abstaining from any act that aims at anticipating the person’s death.

5. Considerations about the “quality of life,” often actually dictated by psychological, social and economic pressures, cannot take precedence over general principles.

First of all, no evaluation of costs can outweigh the value of the fundamental good which we are trying to protect, that of human life. Moreover, to admit that decisions regarding man’s life can be based on the external acknowledgment of its quality, is the same as acknowledging that increasing and decreasing levels of quality of life, and therefore of human dignity, can be attributed from an external perspective to any subject, thus introducing into social relations a discriminatory and eugenic principle.

Moreover, it is not possible to rule out *a priori* that the withdrawal of nutrition and hydration, as reported by authoritative studies, is the source of considerable suffering for the sick person, even if we can see only the reactions at the level of the autonomic nervous system or of gestures. Modern clinical neurophysiology and neuro-imaging techniques, in fact, seem to point to the lasting quality in these patients of elementary forms of communication and analysis of stimuli.

6. However, it is not enough to reaffirm the general principle according to which the value of a man’s life cannot be made subordinate to any judgment of its quality expressed by other men; it is necessary to promote the *taking of positive actions* as a stand against pressures to withdraw hydration and nutrition as a way to put an end to the lives of these patients.

It is necessary, above all, *to support those families* who have had one of their loved ones struck down by this terrible clinical condition. They cannot be left alone with their heavy human, psychological and financial burden. Although the

care for these patients is not, in general, particularly costly, society must allot sufficient resources for the care of this sort of frailty, by way of bringing about appropriate, concrete initiatives such as, for example, the creation of a network of awakening centers with specialized treatment and rehabilitation programs; financial support and home assistance for families when patients are moved back home at the end of intensive rehabilitation programs; the establishment of facilities which can accommodate those cases in which there is no family able to deal with the problem or to provide “breaks” for those families who are at risk of psychological and moral burn-out.

Proper care for these patients and their families should, moreover, include the presence and the witness of a medical doctor and an entire team, who are asked to help the family understand that they are there as allies who are in this struggle with them. The participation of volunteers represents a basic support to enable the family to break out of its isolation and to help it to realize that it is a precious and not a forsaken part of the social fabric.

In these situations, then, spiritual counseling and pastoral aid are particularly important as help for recovering the deepest meaning of an apparently desperate condition.

7. Distinguished Ladies and Gentlemen, in conclusion I exhort you, as men and women of science responsible for the dignity of the medical profession, to guard jealously the principle according to which the true task of medicine is “to cure if possible, always to care.”

As a pledge and support of this, your authentic humanitarian mission to give comfort and support to your suffering brothers and sisters, I remind you of the words of Jesus: “Amen, I say to you, whatever you did for one of these least brothers of mine, you did for me” (Mt 25:40).

In this light, I invoke upon you the assistance of him, whom a meaningful saying of the Church Fathers describes as *Christus medicus*, and in entrusting your work to the protection of Mary, Consoler of the sick and Comforter of the dying, I lovingly bestow on all of you a special Apostolic Blessing.

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*[Mary Lee Freeman is a nurse practitioner. The following essay originally appeared in the January 30, 2004 issue of Commonweal magazine; all the names of patients are pseudonyms. ©2004 Commonweal Foundation, reprinted with permission. For subscriptions, visit the magazine's website at [www.commonwealmagazine.org](http://www.commonwealmagazine.org).]*

### Caring for the Dying

*Mary Lee Freeman*

Friday afternoon at the hospice center. I punch in and eye the “white board,” looking for empty white strips and unfamiliar names, quickly piecing together who has died, who is still living in this eighteen-bed facility. I start at the bottom of the list, Room 19 (no Room 13 here—these folks have had their fair share of bad luck). Room 19 is the stomping ground of the Delgado family. Miguelito, five years old, with his bald pate and big eyes, is speeding up and down the hallways in a motorized Big Wheel. His two older sisters will be coming “home” from grade school soon, and his younger sister, Lily, is being her cute, showboat self, hanging out once again at the nurses’ station while mom naps on the extra bed in Miguelito’s room.

In Room 18 is Faye Niesen, whose family complains about the Delgados, then feels badly about complaining, and then complains some more.

In Room 17 is petite Eleanor Kempe with the gimlet eyes and the protruding abdominal tumors that make this eighty-two-year-old look oddly pregnant as she sits and watches Mother Angelica on EWTN. Eleanor keeps a pocketbook tucked just so at her left hip, under the sheets, and Kleenex tucked just so up the right sleeve of her thin bathrobe. Second only to Mother Angelica in Eleanor’s mind is the Food Network’s Emeril, whose trademark exclamation “Bam!” pops out like bullets from at least five or six rooms on the unit, each night. The Food Network is big here, very big.

In Room 16 is the John Roth family, with Miles Davis on the CD player and pale ale in the cooler. They were hanging out last night, and they’ll be hanging out tonight and through the weekend, spirits never flagging, manners always impeccable, their love for their husband and father and brother deep and wide and joyful.

In Room 15 is Franklin Schuebel, ninety-five years old. Mr. Schuebel desperately misses his wife, who died last year. Each night he waits patiently as I listen to his heart and lungs. As soon as I remove the stethoscope earpieces from my ears, he pops the same disconcertingly hopeful questions about being reunited with his wife. “How do they sound? Are they bad? Do you think tonight might be the night?” “No, Mr. Schuebel, everything sounds pretty good in there. Probably not tonight.” He sighs a resigned, tired sigh. He pats my hand. “Some day,” I say. He smiles broadly.

In Room 14 is Steve Wilkins, forty-eight years old, who will die tonight, and whose seventeen-year-old daughter will scream when he does. It will unnerve

everyone, because we're not used to screamers. Friends imagine that where I work there must be a constant drone of keening and sobbing. There isn't much of that. This seventeen-year-old will cause me to think back, over six years of work on two coasts and in three cities, to the last time I witnessed wailing at a deathbed. The emotion most prevalent here when death comes, as it does almost daily, is relief.

In Room 12 is "Airman" Mike Grable, an African American and former professional wrestler, whose seven children will one day soon accompany his barrel-chested body down the long corridor, past the nurses' station, through the lobby, and out the front door, singing "Amazing Grace" as they go.

The north-wing patients are present and accounted for.

The evening nurses and aides go to listen to the taped report left by the day shift. It is both relentlessly sad and unfailingly hopeful, peppered with facts about vital signs taken, symptom-control efforts made, new physician orders received. A day-shift staff nurse, Mary, the preacher's wife, comes in and interrupts our listening to announce a new admission. Her first words: "Can we just stop admitting the patients with wingnut families, just for a few days? My Lord and Savior, I just cannot handle one more." After the chuckling dies down, we listen closely to what Mary has to say. We don't take the wingnuts lightly, because memories are still fresh of one of our favorite patient's sons being caught in a supervisor's office trying to heist a laptop. Police were summoned, restraining orders rendered. As a result, a Post-It note went on the receptionist's computer identifying another family member not permitted entry to the ward. That note is still there, sitting above the other Post-It listing all the relatives not allowed to receive information about one patient or another. That list is always present—sometimes short, sometimes impressively, depressingly long.

It is a quiet but lively place, this unit. Periodically, ambulance drivers come with their bright orange stretcher contraptions, bearing sedated patients whose pale faces look tiredly out over white sheets and blankets, a small passel of family members bringing up the rear. And while many of these patients end up being discharged to their homes after short stays, a great many of them leave on the black stretchers maneuvered down the corridor by funeral-home attendants, the same small passel of family members bringing up the rear.

What happens while they're here cannot but prompt reflection.

*A dying man needs to die, as a sleepy man needs to sleep, and there comes a time when it is wrong, as well as useless, to resist. —Stewart Alsop*

I am a nurse practitioner by training, and the field of hospice and palliative care is my métier. I have assumed various roles and performed various duties over the years, spending time as a "field nurse" visiting hospice patients and families in their homes, as a hospital-based palliative-care consultant tending to terminally ill patients in the hospital or being discharged, and as a nurse in a freestanding hospice facility.

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Saying that I love this work prompts people to think I must be a saint (that would be a “no”) or a scythe-carrying sicko (ditto, I hope). What attracts others and me to this work, I think, is the privilege of dealing on a daily basis with life in the raw. There is very little that is superficial about caring for the dying. Hospice patients and their stories are a refreshing oasis from the world of artificial hype and imagined crises—not all crises outside a hospice are imagined, of course, but many are. My work requires a daily recognition and acceptance of the human condition. All the parties involved come to understand that, yes, this particular person’s days are numbered, that there will be a death here, and that we will do all we can to accompany this person along the road that leads to death. That is something people need to hear, and participating in such care is not a bad way to use one’s talents.

The theologian Karl Rahner noted, “We do not always dwell at the core of our incomprehensible being, we stay on the surface, we are exiled to humdrum, bustling everyday life. Yet once in a while, we too are thrown into the mystery of guilt, death, forgiveness, and unfathomable freedom that issues from God into the midst of our life.” Hospices do not place “Help Wanted” ads touting “Guilt! Death! Forgiveness! Freedom!” Still, these mysteries—whether spoken about or not, whether explicitly engaged or not—are omnipresent in my work. It is a humbling and enlightening thing to be, essentially, a participant observer in thousands of final scenes.

*May you always do for others and let others do for you.*

*—Bob Dylan, “Forever Young”*

There are a few things one learns, playing a bit role in the lives of the dying and their families. One is that “death with dignity” is an ambiguous term. Another is that suffering is part of the human condition, and trying to stamp it out or ignore it or gloss over it is a dangerous illusion.

In the fall of 2000, Bill and Judith Moyers presented a four-part PBS television series on death and dying. A New York Times op-ed piece about the series revealed that the Moyerses had disagreed about what it should be titled. Bill wanted to call it, *Living with Dying*. Judith, his wife, wanted *On Our Own Terms: Dying in America*. Bill thought that Judith’s title pandered to the worst impulses of Americans about the value of autonomy and self-sufficiency. Judith won, but Bill was right. Life cannot be grasped simply on our own terms. Death, even less so. And yet, “On Our Own Terms” is the way the cultural discussion has taken shape, especially among graying Baby Boomers. “We all have a right to die on our own terms; we all have a right to die with dignity,” goes the mantra.

It all depends. Everyone, from prolife vitalists to Hemlock Society cheerleaders, speaks in terms of “dignity.” Yet the definitions of dignity are all over the map. As a nursing student I read an article by a nurse researcher, Jane Haddock, whose work had led her to posit a summary profile of the “dignified self.” The profile included the attributes of “self-control, control of environment, autonomy, and

independence”—all of which the dying person is hard-pressed to hold on to. Haddock went on to conflate dignity with self-esteem, and to suggest that “to ascertain if one possessed dignity, self-esteem could be measured using a scale.” I doubt it. How does one quantify the language about human dignity in the UN Charter? And what about that tenacious notion that we are creatures made in the image of God? Can we really get out the Likert attitude scales and plot whether someone possesses dignity or not? Sadly, “concept analyses” like Haddock’s, and the mindset they represent, are standard fare in the world of health care. They don’t do us much good in the hospice facility.

If we consider ourselves masters, rather than stewards, of our lives, then dying and death are the ultimate indignity, and the rooms and hallways where I work are filled with indignities piled upon indignities, clear up to the rafters. If our definition of dignity in the dying process is built only on happy accidents like continence, or strength, or the ability to utter profundities until our last breath, or independence—and if we are committed to people having “death with dignity”—then we will panic as strength wanes, Foley catheters need placing, interaction gives way to sleep, and independence mutates into dependence and helplessness. Wanting to dignify death, we soon will want to hasten it.

There is an understandable desire for a neat and ordered segue from life to death. Just ask the state “surveyors” who evaluate and accredit our facilities and who pore over our patients’ charts, looking for evidence that we have, as they put it, “accomplished the goals of the care plan,” and that patients have benefited from our ability to arrange for them freedom from suffering.

Benefit. Freedom. Suffering. All loaded words. Certainly, physical pain ought to be aggressively treated—and only recently have we recognized how often that task is not performed nearly as well as it could be. Yet just as certainly we must resist the temptation to try to stamp out the suffering that comes with our connectedness to each other. Physician Ira Byock talks about the “Five Things” that must be said if there is to be closure in a significant relationship: “Forgive me. I forgive you. Thank you. I love you. Goodbye.” If we imagine that there is a way to get through some semblance of that list and not suffer along the way, I think we are naive.

Acceptance of the human condition—not horror at its indignities—is the best way of combating the influence of those who feel compelled in their own well-meaning way to hasten death’s arrival. In my experience, three things are needed at the end of life: first, a recognition that dignity is something to be honored in people quite apart from their abilities and failings; second, an inclination and a commitment on the part of people—professionals and nonprofessionals alike—to step up and care for dying persons as their ability to care for themselves wanes; and third, a willingness on the part of the dying to allow themselves to be cared for. These three needs are huge and often unmet in a culture that can barely make sense of any of them and supports precisely none of them.

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*Allowing and helping a patient to remain true to individual character and personality to the very end—even if that entails bitterness and anger—is preferable to the uninvited interdisciplinary team of health-care professionals energetically hectoring the dying patient to change personalities at that late date and making the patient feel additional guilt and shame for resisting the thanatologically sensitive experts' injunctions to "have a nice death."*

—Marshall Kapp, *"The Right to Die Mad"*

I read these words to my colleagues, assembled for our weekly "interdisciplinary" team meeting. They laugh heartily, veterans all. For the rest of the meeting, we keep interrupting the social workers' reports: "But did you tell him to have a nice death?" We know Kapp has a point, one we hope we each learned long ago. We only wish the surveyors who assess our performance would embrace it.

Hospice workers have an axiom, "People die the way they live." Although that is not always true, it usually is. Cranky people die cranky. Abusive alcoholics die terrorizing their frightened spouses. Eminently practical people die concerned about eminently practical things. You would not last long working in a hospice if you went around energetically hectoring people to make their way through Ira Byock's list of the five things people need to say to reach closure.

Some patients and families are veritable black holes of need, with generations of sin and dysfunction that hardly lend themselves to easy understanding, let alone tidy solutions, happy deaths, and what the bereavement experts call "uncomplicated grief." Affixed to the wall above my desk is a scrap of paper with this reminder from H. L. Mencken: "For every human problem there is a solution that is simple, neat, and wrong."

Hospice workers know—but sometimes forget—that we are seeing just the tip of the iceberg of people's histories. When my own father was dying at home, I spoke with his hospice nurse by phone from afar and listened to her assessment of my dad's situation. She did—and didn't—have the family pegged. Once home I met her—a wonderful woman—and later, sitting vigil, winced a bit as I imagined her at weekly staff meetings, giving her patient summaries just as I give mine, summing up whole worlds in a few sentences while around the table heads nod knowingly.

I often find myself, when I am visiting patients in their homes, in the position of being the last new person to get to know them, of being the last nonfamily contact with the outside world. Sometimes I am rather absurdly but quite obviously looked to as the embodiment of "the world," as in, "What does the world think of me? How will the world remember me?" Opinions about the dying person are already well established and seemingly unshakable among family members. It is with the visitors from hospice that the dying person has a last chance to be better than he really was. That's fine with me. Quite honestly, I am sometimes thankful for what I don't know about my patients' lives.

As death nears, emotional needs often loom large, but are so seldom spoken. One can do a fair bit of damage energetically hectoring someone to speak them,



but perhaps just as much damage by pretending they don't exist. Spoken or not, acknowledged or not, the needs usually run something like this: I need everyone to know I didn't "give up" against the cancer. I need to know I wasn't a terrible parent. I need to know that the nurse and the aide and the doctor caring for me actually like me. I need to be forgiven.

It is possible to have whole conversations about these topics without speaking a word. A wise hospice physician from Scotland once adapted an old adage to remind his colleagues: "There are three things you need to practice good palliative care: a pair of ears to listen with, a butt to sit on, and a mouth to keep shut."

*Caring asks doing . . . better immersion than to live untouched. . . . yet how will you sustain? —Tillie Olson, "O Yes!"*

It's 9:30 p.m. on the unit. The Delgados have become so many lumps under blankets on the beds, the couch, the floor. I learned that lesson the other night as I unsuspectingly stepped on tiny Lilly as I tiptoed into Miguelito's darkened room to administer, through the "central line" sutured into his chest, his final medications of the day. It is against his grieving father's chest that Miguelito's sedated body will be pressed weeks later after a morning of fright and struggles for air. Death will come that afternoon, quietly, before his doting sisters return from school.

Faye Niesen is asleep, mouth open in a smile, lit by the blue light from the television, her constant companion and security blanket. Soon she will be sent home, and we will hear of her protracted decline but ultimately peaceful death from our field-nurse colleagues.

Eleanor Kempe is awake, waiting for the miracle she knows will come. Hyperalert, she watches me hook her gastric tube back up to suction, removing from her all that she has taken in for supper, all that would never get past her bowel obstruction and so is vacuumed out before it all comes back up on its own. "Do you think the food was in there long enough for my body to make use of it?" Eleanor asks me. She asks everyone—aides, nurses, physicians, volunteers—the same question, night after night, and ponders the vagueness and inconsistency of our answers. She will soon die, no longer expecting a miracle—not devastated and angry, as we had feared, but surprisingly serene.

John Roth's family welcomes me in with smiles. Frank Morgan's Mood Indigo has replaced Miles Davis on the CD player. A daughter follows me out into the hallway. "Those doors to his patio—a bed can fit through them?" "Sure," I say. "We could wheel him out there?" "Sure," I say. A few days later, the sun will be shining, the breeze blowing, and the omnipresent family scattered around the patio when John draws his last breath. Each time there's a "patio death" I think of Saint Francis, hoisted outdoors in his last hour by his own request, that he might die lying upon the cool brown earth.

Franklin Schuebel, sweet Franklin Schuebel, lies still, his face spotlighted by a bit of light from under the bathroom door. I wonder if, after all, tonight is his night, but

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after a long apneic spell, his diaphragm rises up, then gently falls. I move on.

Steve Wilkins's family is restless. Most of them, including his children, I have not met before. The teenage daughter glares at me. She is wired. The whole family is wired. I wish I knew them better. I wish Steve were not dying.

In Mr. Grable's room, one daughter remains. "How do you keep doing this work?" she asks me. "Isn't it depressing?" No matter how many times I am asked that question, it still takes me by surprise. I am not the one with the chronic disease, dealing with the ravages of it on my body and grieving the impending loss of my life and all that is dear to me. Even more to the point, I am not a family member who has been shouldering the multiple burdens of caregiving, of medical bills, of contemplating life without my beloved. It is a strange thing to walk the hospice hallways, amidst such suffering, and to have a question posed about my sustenance.

I am tongue-tied not only because the question seems directed to the wrong party, but because I struggle to put acceptable words to the images and feelings that crowd my mind. "Should I just say it?" I think. "Should I just say, I pray?" For the Dorian Gray families, ugly from decades of sin and dysfunction; for the relentlessly cheerful patient with ALS who smiles even as she cries about no longer being able to walk in the woods and weed her garden; for a twenty-six-year-old patient's mother, stricken and wide-eyed, absolutely certain that her lapsed Lutheran son will be going to hell; for the family of a strong and vibrant colleague who just weeks before had been bathing patients but then occupied a room of her own among them, preceding into death many of those she had bathed. In prayer, as in life, the neat categories I have given above—patients, families, professionals—all meld one into the other. We are all the living; we are all the dying, all of us sustained by grace and mercy and love.

## APPENDIX C

*[Joseph Bottum is the Books & Arts editor of The Weekly Standard. This editorial appeared in the February 2, 2004 issue and is reprinted with permission. © Copyright 2004, News Corporation, Weekly Standard, All Rights Reserved.]*

### No Abortion Left Behind

*Joseph Bottum*

How much is worldwide access to abortion worth? What price are the international activists who cluster around the United Nations willing to pay to achieve the ability of any woman—at any place, for any reason—to have an abortion?

We might start with the deaths of more than 6 million children *after birth*. Of the world's 10 million children who died last year of preventable diseases and starvation, two-thirds could have been saved by effective international intervention through UNICEF, according to a recent essay in the British medical journal the Lancet. But Danny Kaye's old international children's fund has been taken over by abortion activists who have radically shifted the organization's focus away from rescuing children.

Jim Grant, the widely respected executive director of UNICEF, launched what he called the "Child Survival Revolution" in 1982. Upon Grant's death, however, the Clinton administration demanded the appointment of New York activist Carol Bellamy. And under Bellamy, UNICEF has decided its job is not to save sick and hungry children, but to join the great march toward universal sex freedom—agitating for minors' access to condoms, requiring that refugee camps provide abortion services, and handing out sex-education manuals to grade-school students in the third world. "We, a group of concerned scientists and public health managers, call on . . . UNICEF . . . to act on behalf of children," the authors in the Lancet pleaded. "Child survival must be put back on the agenda."

A worldwide decline in democratic government, too, is apparently a small price to pay for bringing about the universal legality of what international documents call "reproductive rights." Why should voters be consulted about the laws that govern them—if consulting actual citizens might not bring about the all-trumping right to abortion? That, at least, is the feeling manifest in recently obtained internal memos from the Center for Reproductive Rights, a lawyers' nongovernmental organization (NGO) that specializes in suing local and national governments that fail to allow unfettered access to abortion.

A copy of these abortion-strategy memos was mailed anonymously late last year to Austin Ruse, who heads the Catholic Family and Human Rights Institute. Rep. Chris Smith of New Jersey reprinted them in the Congressional Record on December 8, and they make fascinating reading—for they show how NGO activists speak behind closed doors. "There is a stealth quality to the work," one memo noted. "We are achieving incremental recognition of values without a huge amount of scrutiny from the opposition. These lower-profile victories will gradually put us in a strong position to assert a broad consensus around our assertions."

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Such disingenuousness is necessary for the abortion activists' strategy, which consists primarily of inserting vague passages in as many international treaties, reports, and working papers as possible—and then getting the enforcement agencies and entities such as the European Court of Human Rights to interpret those passages to mean a universal right to abortion has been established. Although the phrase “reproductive rights” is omnipresent in U.N. documents—a draft for the 1999 report from the Cairo + 5 conference, for instance, used it 47 times in the section on adolescents alone—there is not a meaningful definition of “reproductive rights” in any official U.N. resolution.

Perhaps the most interesting portion of the memos from the Center for Reproductive Rights is the admission that this strategy has failed thus far to establish the “soft norm” of abortion—for the center claimed exactly the opposite two years ago when it brought suit against the Bush administration for reinstituting the ban on federal agencies' funding of international organizations that promote abortion. In its brief in that case, the center explicitly insisted that the performances of international courts had already established a “customary right to abortion” that American courts are obligated to obey. “Our goal is to see governments worldwide guarantee women's reproductive rights out of recognition that they are bound to do so,” the center's memos admit—and, “What good is all our work if the Bush administration can simply take it all away with the stroke of a pen?”

The cease-and-desist letter the center's president sent Austin Ruse after these embarrassing memos were leaked to him is hilarious in its arrogance and frankness. The memos are “privileged communications, proprietary information, and trade secrets” that must be returned unused, since “disclosure of this material has caused, and further disclosure will cause, CRR irreparable harm.” And the harm is, finally, the revelation of the circularity in the abortion activists' technique. Their legal briefs routinely cite phrases they themselves crafted in U.N. directives, international court decisions, and treaty-organization minutes. Every time a court admits one of these “soft norms”—as the U.S. Supreme Court did in its Lawrence decision last June—the activists move closer to achieving their goal.

The memos from the Center for Reproductive Rights are hardly the long-sought smoking gun that at last exposes the schemes of the pro-abortion NGOs. Freshly fired pistols litter the floors of the United Nations and the World Court—all the treaty organizations at which the world's legal and practical norms are decided these days. At the Cairo world conference on population and development in 1994, or the Beijing conference on women in 1995, the international community did little to hide the centrality of its abortion agenda or its disdain for the opponents of abortion.

But the memos do at least reveal the extent to which the activists for international abortion hate the forms and participatory nature of democratic government. These people are fanatics, in the truest sense of the word: All other issues must be warped to reflect solely their concerns, and the mere existence of opposing views convinces them that radical evil is afoot in the world. Their adversaries seem to

them demons and monsters, against whom no tactic of deceit or slander is ever forbidden.

Various women's groups this summer, for instance, denounced the government of Peru—because the Peruvian congress apologized for the more than 200,000 poor women coerced into sterilizations under the 1990s “compulsory family planning program” of President Alberto Fujimori. “We do not condone forced sterilizations,” one activist explained, “but no one can deny that Fujimori’s program was excellent in terms of access and information.” The Center for Reproductive Law and Policy issued a press release declaring the “apology is part of a right-wing strategy to limit family planning options in Peru.”

This November, Ellen Sauerbrey, representing the United States on the U.N. Commission on the Status of Women, promoted a mild resolution—“very near and dear to us in America,” as she explained—that urged greater political participation by women around the world. Nineteen pro-abortion NGOs promptly sent a letter to the U.S. ambassador to the U.N., John Negroponte, rejecting the resolution because it didn’t mention abortion.

The examples of fanaticism go on and on. UNESCO has drifted so far into the abortion fight that an irritated Tommy Thompson, secretary of health and human services, finally sent a letter this month to the U.N. asking what declarations such as “Governments should make abortion legal, safe, and affordable” have to do with UNESCO’s supposed mission of promoting education, science, and culture. When Secretary of State Colin Powell cut off American funding for the United Nations Population Fund in 2002—on the reasonable grounds that UNFPA was hopelessly implicated in China’s forced-abortion policy—he was immediately attacked by E.U. development and humanitarian aid commissioner Poul Nielson, for creating a worldwide “decency gap” in failing to help UNFPA spread international abortion rights.

Meanwhile, Douglas A. Sylva, the vice president of Ruse’s group, reports that the U.N.-backed European Population Forum this month blamed the United States for bringing, as one official put it, “near-collapse to international gatherings on children’s rights, development and population by opposing any language that might allow for abortion.” The fundamental job of *every* international agency in coming years, the president of International Planned Parenthood explained, will be to fight the opponents of abortion by “discrediting their pseudo-science and unmasking their ideological motives. It is essential to demonstrate the truly dangerous consequences of their approach.”

Only zealotry and extremism can explain all this: the warping of every institution, every issue, and every occasion to concern abortion. The pro-abortion fanatics have taken over the entire international forum. And to achieve the ability of any woman—at any place, for any reason—to have an abortion, they are willing to pay any price. —*Joseph Bottum, for the Editors*

## APPENDIX D

*[Pia de Solenni is director of life and women's issues at the Family Research Council. The following appeared on National Review Online (nationalreview.com) on March 9, 2004 and is reprinted with permission.]*

### Hearing Women

*Pia de Solenni*

You know the famous blob of tissue that Americans have been arguing about for more than 30 years? Well, it turns out that the women who have abortions have about as much standing as that “product of conception.”

Last week, Senator Sam Brownback (R., Kan.) sponsored hearings in the Senate to review the impact of abortion on women and, ultimately, to call for greater research. Note well, this was not intended to be an abortion debate. Rather, it was meant to offer a close look at the effects, positive or negative, of abortions on the women who have them.

Approximately 40 percent of American women under 45 have had at least one abortion. Twenty-five percent of all pregnancies end in abortion. Since the legalization of abortion in 1973, over 40 million abortions have taken place. Yet no comprehensive data exists concerning the impact of abortion on women. Consider that the federal government has in place mechanisms to track just about every other medical procedure, but it chooses not to follow this one.

Consider also the responses of the pro-choice voices present at the Senate hearing. When asked by Senator Brownback, “So you don’t want to know the data?,” Dr. Nada Stotland, professor at Rush Medical College in Chicago, replied, “It’s hard to impute [the effects] to a procedure that they had for five minutes.” This she said after the testimonies of Georgette Fourney and Michaelene Jenkins, both women who have had abortions, suffered from them, and are active pro-life leaders. In essence, Dr. Stotland was saying that their experiences, no matter how personal, no matter how painful, don’t matter.

Let’s hear what others had to say. Senator Frank Lautenberg (D., N.J.) commented to these two women who had just spoken of their traumatic experiences, “Your personal experiences are interesting. . . .” But he didn’t understand why it’s an issue at all, when an abortion can be “as simple as a pill the next day.”

The Rev. Dr. Roselyn Smith-Withers, of the Religious Coalition for Reproductive Choice, offered her testimony from the perspective of one who regularly counsels women who have had abortions. She commented that women “can learn from that experience [abortion].” (Now there’s someone who will feel your pain.) She also explained, “Women who had great visions for themselves are often diminished by having children.” The 75 million women who are mothers in this country would probably have something to say about that.

While each abortion advocate maintained the importance of abortion access, not one would admit the importance of research on abortion and its effects on women, a strange fact considering that they argue in behalf of women’s health.

From a scientific perspective, Dr. Elizabeth Shadigian, professor, researcher, and ob-gyn, provided perhaps the clearest voice. In her testimony, she explained that while we may have sufficient information on how to perform an abortion or how to deal with the immediate complications of an abortion, we have few studies concerning long-term complications. The issue has been so wrapped in politics that we have not been able to discuss the truth of the matter at hand.

Based on the limited research available, Dr. Shadigian noted four conditions that research has shown to be related to abortion: breast cancer, placenta previa (when the placenta covers the cervix, thereby making it necessary to deliver by C-section), pre-term birth, and maternal suicide.

To date, there is no mandatory reporting of abortion complications in the U.S. Surely a medical procedure that affects over one million women a year would be worthy of careful monitoring—unless the lives and health of these women are expected to be sacrificed to a particular political ideology.

For every other medical procedure, health-care providers must inform patients about the benefits and risks of the treatment. In the case of abortion, a woman's right to privacy means that she is so isolated in her decision that she is not even given full knowledge of the treatment she has "chosen."

Unfortunately even professional organizations like the American College of Obstetricians and Gynecologists (ACOG) are not exempt from political bias either. Dr. Shadigian, member and fellow of the ACOG, cited the organization's opinion from its *Compendium of Selected Publications, 2004, Practice Bulletin #26*:

Long-term risks sometimes attributed to surgical abortion include potential effects on reproductive functions, cancer incidence, and psychological sequelae. However, the medical literature, when carefully evaluated, clearly demonstrates no significantly negative impact on any of these factors with surgical abortion.

Interesting. Despite the fact that medical research shows a link to at least four serious conditions, none of them falls under the criteria of "significantly negative." Since when is maternal suicide a good thing?

Such interpretations of the limited scientific material available can only be due, at best, to ignorance of the facts resulting from blind ideology. In fact, this ideological commitment is so persistent that it refuses to submit itself to the light of authentic science and medicine.

The hearing was intended only to make the case for routine research and study, to better enable women to give informed consent. It was not about abortion per se. From the comments given by the abortion advocates who participated in the hearing, it's clear that they deny the sacredness and inviolability of both the unborn child's life and the mother's life. For our part, pro-lifers maintain that both lives are entitled to the full protection and acknowledgement of their rights. That's why pro-life groups also serve women who have had abortions.

## APPENDIX E

*[Robert Hart is an Anglican priest and the Vicar of St. Andrew's Chapel, a Continuing Anglican parish in Easton, Maryland, where he lives with his wife and three of their four children. The following originally appeared in the April issue of Touchstone: A Journal of Mere Christianity (www.touchstone.com) and is reprinted with permission. Copyright © 2003 the Fellowship of St. James. All rights reserved.]*

### Her Mother's Glory

*Robert Hart*

I promised myself that I would not be the stereotypical father of the bride, like Spencer Tracy, who hates to give away his little girl. But as I walked her down the aisle, and approached the moment she would become a full-grown, married lady, I felt everything I had determined not to feel. Very far from my mind was the story of her strange origins. It is always far from my mind, unless something reminds me of it, like the recent news from Poland.

The infamous abortion ship from Holland was daring to stop off a port in Poland in order to make its “services” available to Polish women who do not have “reproductive rights”—as the anti-life crowd call them—in their own country. Polish law restricts abortions to cases in which the mother's life is threatened, to cases of incest, and to cases of rape. Compared to the ease with which most women in the Western world can obtain legal abortion for any reason, in fact for no reason at all, and at just about any time during pregnancy, Poland is better. But pro-life? No, sadly, no.

#### His Daughter Alone

Of my four children, my daughter alone is the one I adopted. I never exactly forget the fact; it simply passes out of conscious thought since it does not matter, for she is, in every way that counts, my daughter, my first child. Over the years, I have always felt what a father ought to feel.

When she was eleven, she suffered a staph infection, and Diane and I feared we would lose her. This was the second time in her short life that she was in danger of dying. The first time she was in danger she did not face an impersonal disease, but determined persons: when her mother had to fight against intruding social workers, and the whole system, for the right to make the choice that her baby would be born. After all, when a woman has been made pregnant through rape, it is not only her right, but her duty, to do the “honorable thing.” At least, so it seemed from all the pressure put on her in those months. She was upsetting the expectations and demands that “liberated” women have no right to upset. She was refusing the “sacrament” of abortion.

What a terrible thing she did. For a woman to bear a child when abortion seemed so justified, so necessary, when the pregnancy was the result of rape—well, it was certainly anti-social behavior. She was coerced into seeing a psychiatrist who could help her overcome the obvious defect known to Christians as principle. He might



even have cured her of maternal instinct and the malady called love.

But all those years ago I knew nothing of what had happened, only that she was suddenly gone, nowhere to be found. Why had this girl vanished from our hometown in Maryland without a trace? When I discovered her whereabouts, 3,000 miles away in California, I hastened to call her. I had expected, had hoped, to have seen her in those months. "I have a baby girl," she told me.

"Are you married?"

"No."

"I see. Well, as a Christian I hope you have repented of . . ."

"Well, it was from rape, actually."

I found that she would not put up her child for adoption. She was willing to live as a single mother because she could not be sure that a couple would raise her child to believe in Jesus Christ. She decided to keep the baby; and God rewarded her by giving her a wonderful, not to mention dashing handsome, husband.

#### **Convoluting Reasoning**

I never think of my daughter's origins and the strange circumstances of her early life unless something brings them to mind; for example, the disappointing remarks of a "conservative" radio talk-show host. This fellow talks a lot about his Catholic faith and Irish heritage, so it was with some astonishment that I heard him defending his view that abortion in cases of rape may be justified. "After all," he pointed out, "it's not the same as when it's someone's fault that she is pregnant. I just think it's different." He certainly did not get this idea from the Catholic Church.

I remembered back over twenty years ago hearing the same convoluted reasoning from Christians, some Catholic, some Evangelical. I recall a very Evangelical and Charismatic lady asking me, "But if it was rape, why didn't she get an abortion?" I thought about the king of Judah, the one who would not execute the sons of his father's assassins because of the Law of God, which says "the children shall not be put to death for the sins of the fathers, nor the fathers for the sins of the children" (2 Chronicles 25:4; Deuteronomy 24:16).

Where did the "conservative" radio talk-show host get the idea that pregnancy is a penalty? If it is a penalty, it might be unjust for the innocent to bear it. But what if it is not a penalty? What if it is the healing that God might give to a woman who has suffered a violent attack? What if the Author of Life takes the opportunity to do good from someone's evil? The injustice done to Joseph resulted in the saving of his life, and that of millions of people, foreshadowing the good done for the whole world by the unjust crucifixion of a young rabbi from Nazareth. It is ever the way of God to make good come from the evil that men do.

Just who is it that these well-meaning people, such as the very Charismatic lady and the talk-show host, would sentence to death?

I remember the very wide eyes of a ten-month-old baby girl looking up at me, having just arrived by plane from California with her mother. I remember her first steps across my parents' living-room floor. After her mother and I were married, I

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remember the first Christmas in our apartment, and her excitement at the wonder of a lit and decorated tree. She had names for us from Winnie the Pooh. I was Pooh, she was Piglet, and as she looked at her mom, now pregnant with the first of our three sons, she said, “And mom’s the kangaroo.”

Her very first day of school I remember watching her bravely walking into the classroom, as a lady laughed at the sight of my perplexity—a feeling of mingled loss and pride that was small compared to what I felt when I gave her in marriage to a fine young man. I remember her saying to him, “I do,” and pledging her life not only to him but also to any children they are blessed with, and to God who blesses them.

She is a young lady who spreads joy wherever she goes. She has a place in the lives of many, not only her new husband, her parents, and her brothers, but many who know her well, and many who have met her in passing—a unique place that no one else could fill. She is happy by nature at 23, married, an avid reader, a good friend, a serious Christian. This is the person that these well-meaning people were willing to sentence to death. Oh, not now, not when they can see her; but when she was in danger the first time, in the womb and hidden from view.

### **Enough for Her**

My wife is not living the life of a tragic victim. She is the happy mother of four children, and would not wish to part with any of them. My daughter learned of her origin after she was over twenty years of age and it became obvious that the truth could not be hidden without confusion. Someone had taken pictures of her as a three-year-old, at the wedding of her parents. I had been warned, “Never tell her, it would devastate her to know.”

Not so. Rather, the mystery was unsettling, and the truth was welcome. You see, it did not matter. She had always known that God is the Author of Life—all life. Every human being is made in his image, and that means everything when a child is raised to understand that the image of God became more than an abstract idea in Hebrew Scripture when the Word was made flesh and dwelt among us. And it was enough for her that she has a mother and a father who love her.

For both Diane and me, the details of our daughter’s early life and strange origins are very much out of mind, far from conscious thought. That is, unless something brings them to mind, such as realizing that it is time to tell our story for the benefit of others who are caught in what seem like desperate circumstances, and who need the courage to make the decision to let the Author of Life do his healing and creative work, bringing light out of darkness and good out of evil: who need to make the decision of love.

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