

# Physician Assisted Death: Are We Asking the Right Questions?

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*By Barry Corbet*

It's so deceptive, this one simple question: Should we make it legal for people to secure a doctor's assistance in hastening death? Yes or no? Ask, and you might get a definitive answer. Ask why, and what you'll get is slippery, contentious, anything but definitive. Yet we hold to our polarized answers and we do, by God, love them. In our crowd, to take a renegade position is to invite our own public beheading. The wise stay out of it. But we can't. Since virtually all people who request hastened death have old or new disabilities, we're essential to the debate. Death-with-dignity laws are about us.

The discord begins with a name--whatever we're going to call death requested by a patient and facilitated by a physician. The most commonly used term is physician-assisted suicide, or PAS. In disability circles, that acronym stands for personal assistance services, so is rejected here. Not Dead Yet, a major player in the debate, prefers physician-induced death, or PID. It has undertones of medical murder so is rejected on the basis of bias. For this discussion, I've compromised with physician-assisted death, or PAD.

Some background: Suicide is legal in every state, as is passively attending a suicide. Euthanasia, actively helping someone end their life, is illegal in every state. PAD, a physician providing a lethal dose for a patient to take without further assistance, is legal only in Oregon.

Two disability rights-based organizations have formed to address the PAD question: Not Dead Yet, which opposes PAD and the Oregon law, and AUTONOMY, which endorses both. The Hemlock Society has been given much weight because it is the country's oldest and largest group supporting PAD and often incurs NDY's and AUTONOMY's wrath.

In attempting to understand PAD, I've viewed it from three perspectives, each raising progressively harder questions: PAD as personal preference, PAD as a disability issue and PAD as public policy. The categories overlap, but they guide us toward asking the right questions.

## **PAD as Personal Preference**

As president of The Hemlock Society, Faye Girsh (now vice-president), asked me what seems like a reasonable question: "Why can't those who don't want hastened

death live out their full lifespans and those who do want it have this humane option available to them?" Girsh meant the question innocently, but is it truly benign? Not if it's the alpha and omega of the discussion. It sweeps way too many valid concerns under the rug, even on a personal level.

You may feel comfortable in your decision that under certain circumstances you want PAD. You've talked to your family, doctor and hospital, and given everyone copies of your advance directives, the legal documents that state your wishes. You've entrusted your medical power of attorney to someone close. But did you know how easily your advance directives, and therefore your life-and-death choices, can change or be completely ignored?

"In an ideal world, advance directives include individual decisions based on personal consultation with a physician," says Lauri Yablick, a Tucson psychologist who works with people with disabilities. "How can there be informed consent without that?"

Yet by law, on admission to a hospital or nursing home, you must be asked if you have, or want to create, advance directives. At each readmission, the question is repeated. That means an untrained clerical worker often solicits a life-or-death decision from a sick or forgetful patient, an uninformed relative or a court-appointed guardian. Just sign the orange form, honey, and we'll get you in bed.

"Each new admission brings the potential for a surrogate decision-maker to override the pre-existing directive," Yablick says. "I've found inconsistent advance directives on more charts than you can imagine. And the options are pared to a dichotomy. No matter what your advance directive says, your chart says 'full code' [save me no matter what] or 'DNR' [do not resuscitate]. No one's considering clauses like 'meaningful chance for recovery.'" We should find this unsettling. If advance directives can change, how can we have PAD and feel confident that we're following the person's wishes?

But you're a take-charge person, you can make things happen your way. Or can you? You may be unconscious when the time comes, or demented, declared incompetent or taken to an unfamiliar hospital. Your appointed surrogate may have died or your doctor retired. Dozens of things can change, and you aren't in charge anymore.

And how realistic are our ideas of what is acceptable health in the future? "Before your accident would you, fairly, have been able to project yourself into the life you've led since your injury?" Yablick asks. Not a chance. We may say we are not willing to live with certain physical or mental states, but do we really know what we're afraid of? Sometimes the fear is disproportionate to the reality.

What about the limited solace of any plan to get out before the going gets too tough? If you've laid in a supply of barbiturates to take before you fade into dementia, you have to act while you're still mentally and physically capable. You could wait too long or you could make a preemptive strike too early, losing valued months or years.

I confess to a painful preoccupation with this point. My mother and maternal grandmother both had Alzheimer's disease, and neither enjoyed it. Three generations of our family didn't either, and I don't want to follow that path myself or subject my children and grandchildren to its furies. I have a vested interest in PAD.

Yet with or without such concerns, you might find powerful comfort in having that bottle of Nembutal in the cabinet whether you use it or not. No matter how much you love life now, you can still hope to control how and when you depart.

## **PAD as a Disability Issue**

### **Not Dead Yet**

Here's another reasonable-sounding question, this time from the late Drew Batavia: "Disability rights are about autonomy and self-determination. Why shouldn't that freedom of choice extend to end-of-life decisions?"

Because, NDY might say, the current state of institutionalized prejudice against people with disabilities turns that choice into no choice. Because nondisabled people seem to fear disability more than death. Because doctors are fallible in diagnosing and treating depression and estimating life expectancy. Because the current rush to cut health-care costs conflicts with our need for lifelong care. Because PAD can be seen as the ultimate sanction, the ultimate form of discrimination.

Our PAD "choices" may, in fact, be subtly conditioned. "The problem is that our desires are so malleable and manipulable," says Harriet McBryde Johnson, a disability rights attorney from Charleston, S.C., and a supporter of NDY. "You know how easy it is to internalize other people's expectations, how exhausting it can be to oppose them, especially when you're sick. What we confront usually isn't homicidal hate, it's that pervasive assumption that our lives are inherently bad. That attitude can wear us down to the point where we want to be killed."

Can't we build ironclad safeguards into the law?

"Safeguards as presently proposed," counters Johnson, "are about defining a class whose desire to die may be presumed rational, because of illness or disability so 'bad' that no 'reasonable' person would want to endure it. That whole veneer of beneficence. The law has the power to validate and structure prejudice. These [PAD] laws tell suicidal newbies that yes, it really is as bad as it feels, and don't expect it ever to get better. They tell the larger society that disability and illness equal misery, so there's no need to bother about making our lives good. There's an easy way out."

Johnson acknowledges the possibility of individual situations where assisting a suicide or looking the other way might be morally right. "But I wouldn't try to objectively define those situations and build law around them," she says. "It just can't be done. Killing is too serious to manage by checklist."

And what of our physical vulnerability? "We are living the lives that others fear," says Johnson. "I depend on others to keep me alive every day. If I'm lucky, I get them to honor my requests--and keep me alive--on the strength of my paychecks and my charms. But money and charms are transient and, at bottom, we need people to know they're stuck with us no matter what and that they'll see us through those days when we feel bad about the pressures we put them under or when we get tired of all the complications."

With PAD, insurers may be less inclined to see us through. As a class, we're both poor and expensive; beer income, champagne needs. We're the medically unattractive. Of course we fear that insurers will deny us expensive treatment options while holding out the carrot of "a peaceful and dignified death." The cheapest care is no care.

If eligibility for PAD is based on health status, then what is health status? It's a construct grounded in the medical model, and doctors are its arbiters. Yet doctors have a singularly vivid sense of how rotten our lives are. According to several studies, they underrate our quality of life and overestimate our depression, and those perceptions do affect the treatments they prescribe and the advice they give. Given both PAD and prospective payment, will they be too quick to write us off?

We may help them do it. All it will take is one sympathetic health-care worker reporting our ambivalence, however momentary, about staying alive. Then the wheels can turn, doctors can agree that our lives are unendurable, and we can be hustled off to hospice amid a nauseating chorus of people saying we're dying the way we wanted to. With absurd ease, we can be put out of our "misery" with no malice on the part of any segment of the health-care system. It happens now. Is this freedom of choice?

### Autonomy

We are not a right-to-die group," wrote Drew Batavia, the president of AUTONOMY until his death in January. "We are a disability-rights organization that supports our right to decide issues of our lives. The unifying theme is choice and control."

Batavia and Hugh Gallagher co-founded AUTONOMY partly to fight Attorney General John Ashcroft's efforts to nullify Oregon's Death With Dignity Act, partly as a reaction to NDY. Batavia felt that while the leadership of many disability-rights groups opposes PAD and presumes to speak for all of us, many of the rank and file support it.

He may be right. In a 2001 Harris Poll, 68 percent of people with disabilities polled nationwide favored PAD. A small study by Pamela Faden shows a fairly even split, but she warns against using her survey to quantify consensus. Her study does show that many members of disability-rights groups fear criticism if they speak out in favor of PAD.

Batavia--but not necessarily AUTONOMY--saw personal autonomy as the primary goal, and solving social issues that surround PAD as secondary. This is not to say Batavia ignored such issues. To the contrary, his fingerprints are all over key legislation to remedy them.

"Assisted suicide," he wrote, "cannot be held responsible for the consequences of our society's failure to provide adequately for the needs of many people with disabilities." Jack Kevorkian? "Kevorkian demonstrated why laws like the Oregon Act are necessary. He operated without standards." People with nonterminal conditions? "I admit to some ambivalence about this issue," Batavia wrote in 1999, but he included only terminal conditions when speaking for AUTONOMY. And always, Batavia returned the discussion to choice. "Our overall mission," he said, "is to provide a full range of options for people with disabilities." And elsewhere: "Our positions are based fundamentally on the value of autonomy."

Gallagher, like NDY, objects to Hemlock's use of the word "hopeless" as a criterion for hastened death in much of its literature. "A sense of hopelessness is a call for help in living, not dying," he says. He emphasizes that AUTONOMY wants personal control during the dying process, not hastened death for people struggling with life.

Do the Oregon law's guidelines, as Johnson suggests, simply define a class considered better off dead? "Absolutely not," Gallagher says. "The Oregon law is reactive, not proactive. ... It has the support of a large majority of its citizens. It's an insult to say Oregonians believe their terminally ill loved ones are better off dead. It cheapens and polarizes a serious moral issue."

Gallagher is not looking for conflict. "This is not a game of one team opposing another. Different people, cultures and religions hold different positions. These positions must be respected. AUTONOMY believes it should be up to the individual. Our whole purpose is to reduce the vulnerability of disabled persons to outside influence. We are grown-ups and we don't need Ashcroft telling us what we can or cannot do."

And Gallagher sets out his own credo: "I have fought hard to live my life as I choose to live it, to make my own life decisions. I will not give up this autonomy of decision making on my deathbed."

### **The Hemlock Society U.S.A.**

Since Hemlock is headquartered in Denver, I know several of its principals. They are good, intelligent people who wonder why we demonize them and, equally, why we don't see that they promote choice, not coercion.

They don't want to kill people with disabilities. They don't want to kill anyone. They don't provide physical assistance in hastening death. They do provide counseling, information and support. They do support PAD legislation. They want all possible supports at the end of life, and oppose suicide for emotional or financial reasons.

They say they address the agonies of dying, not the tribulations of living.

At Hemlock's heart is its Caring Friends program. Caring Friends, trained and certified by the national office, respond when a member asks for help in hastening death. The Caring Friend visits the member and family, then refers the case to Denver for evaluation.

"When the Caring Friends Program accepts a case," says Girsh, "it is with medical records and a great deal of assessment. Since each case is decided on its own merits, there is often disagreement on the committee about the cases it will accept. This becomes especially difficult when we have people 85 and older asking for our assistance because they have macular degeneration, arthritis or other ailments that make them miserable but will not cause death."

Some will see red flags in this statement, which reflects the Caring Friends program's policy of assisting people who are "suffering from an irreversible physical condition that severely compromises his or her quality of life."

All disabled people have irreversible physical conditions. Most nondisabled people think these conditions compromise our quality of life. In contrast, Compassion in Dying, another mainstream right-to-die group and a key force behind Oregon's Death With Dignity Act, supports PAD only for people who are terminal.

"We go a little further," says Girsh. "We assist in both terminal and hopeless cases." She points out that Hemlock does not use "hopeless" as a criterion in proposed legislation, yet its Web site is riddled with the word--hopeless, hopeless, hopeless.

I ask the obvious question. "So why not provide hope? Why not target the hopelessness?" "We provide hope," she says.

Hemlock provides information on two methods of "self-deliverance," barbiturates and helium--the latter for those who can't get barbiturates and are willing to place a bag over their heads and inhale gas from a tank. Helium has its advantages; it's quick, certain and available.

I mention to Girsh that an old friend, a retired physician and Caring Friend, recently attended the death from helium inhalation of a woman with "relentlessly progressive multiple sclerosis which had left her essentially immobile." He was impressed with the thoroughness and sensitivity of Hemlock's counseling and the speed and peaceful nature of her death, but had one misgiving. "She wasn't truly terminal," he said. "I had a very slight concern as to how much of her motivation was related to her parents, whose lives had been totally turned upside down for four years of 24-hour caregiving. But there was certainly no compulsion and, to the contrary, much love."

Girsh is familiar with the case and knows the family. "So what should we have done?" she asks. "Money isn't the problem. Love isn't the problem. Care isn't the

problem." I say something weak about community supports but I really don't know what might have helped short of a turnaround in how our society views disability.

"Truly," says Girsh, "I would like an answer from our critics. Why can't some organizations fight to make life better for people with disabilities and others deal with the reality that death is coming to all of us and it needn't be brutal, lonely or agonizing?"

Yet Hemlock, through conflicting statements by its leaders, has been largely responsible for the copious ill will that exists between the disability community and the right-to-die movement.

Derek Humphry, Hemlock's founder, has taken heat for advocating "justified suicide by a handicapped person," and there's this oft-quoted chestnut from Janet Good, founder of Michigan Hemlock: "Pain is not the reason we want to die. It's the indignity. It's the inability to get out of bed or get onto the toilet, let alone drive a car or go shopping without another's help. ... Most of them say, 'I can't stand my mother--my husband--wiping my butt.' That's why everybody in the movement talks about dignity. People have their pride."

They do, but are driving, shopping, continence and self-buttwiping prerequisites?

A recent public-relations disaster occurred when Hemlock invited Philip Nitschke to address its national conference in San Diego. Nitschke, an Australian campaigner for euthanasia, advocates making "rational suicide" available to everyone from troubled teenagers to lonely old people. At the conference, he called Kevorkian a hero and offended many Hemlock members by his immoderate zeal for suicide. Hemlock, for the record, has distanced itself from Kevorkian, and may now be edging away from Nitschke.

It hasn't helped that Nitschke receives funding from Hemlock to design machines people can use to kill themselves, or that he assisted in the very public death--21 family members and friends attended--of euthanasia advocate Nancy Crick, who reportedly was dying from a recurrence of bowel cancer. A postmortem found no sign of cancer, and Nitschke later admitted he was aware of Crick's cancer-free state.

But organizations can learn and change, and there are signs that Hemlock is doing just that. Paul Spiers, a T6 paraplegic who will take office as board chair in July, says he's committed to improving communication and healing wounds. Soon Hemlock will make another effort to alter its public image by changing its name. Look for an announcement this summer.

### **PAD as Public Policy**

A good friend with Parkinson's disease killed himself some years ago. He had talked to his inner circle, giving most of us a chance to talk him out of it, and we failed him utterly.

Once he'd decided to die, he tried to direct the exhaust of his car into his house. Neighbors kept walking by, and he decided the effort was entirely too public. He slit his wrists, but didn't bleed fast enough. "It's like *The Three Stooges Commit Suicide*," he wrote in his journal. Finally he succeeded in hanging himself. It was awful for him, awful for his friends.

Most unassisted suicides tend to be grotesque. They're violent or fail or create new disabilities. They exclude loved ones at a time when closure is needed. Wouldn't the option of PAD be better than that?

"I think it ought to remain difficult and messy," says Harriet Johnson, "something you'd think about pretty hard before doing. I don't see every suicide as irrational or even tragic. However, I have no trouble following NDY in toto when it comes to the law, which is what NDY is really about. Killing should remain a criminal act. When it's discovered, we should prosecute. But the law isn't the same as justice and never will be. It serves too many conflicting purposes to represent any kind of ideal."

So to serve justice, at times, we should ask someone to bend or break the law for us? That's hard on the someone else.

"As it ought to be. Gut-wrenching, bone-chilling agony."

My friend was very far from terminal, which raises another sticky question: Johnson thinks Oregon's restriction of its PAD law to people with six months to live is suspect. "It's really illogical to give them, and only them, the right to a quick and easy out. I agree with Kevorkian that if anyone 'needs' death services it's people with a long life expectancy who are miserable. I don't quite understand why the lines are drawn the way they are. But then, I reject the whole idea of line-drawing."

So we should offer PAD to everyone or no one?

"To no one."

"I believe that whether or not to continue living is as personal a choice as anyone could make," says Lauri Yablick, "and that helping people die is potentially as valid a role for health-care providers as helping them live." But legalizing PAD? "No. Not here, not now, and given our health-care system, not for a long time. This is such a complicated issue and people want to treat it so simply."

Yablick questions the Oregon law's lack of consistency and inclusion. "The Oregon Act excludes most people with mental conditions. Who sold the myth that we can make a clear, reliable and objective determination of competency and emotional stability? Where's the logic in excluding people with depression and other serious mental illness--groups with the highest rates of suicide--from the sanctioned version? Won't people with progressive dementias still feel pressured to act prematurely? Who decided that physical suffering trumps emotional suffering?"

"Another great fallacy is that regulations prevent abuses," she says. "[The] Ten Commandments didn't bring a loving and peaceful world. More laws didn't bring fewer prisons. And the regulations intended to prevent other health-care abuses have failed miserably. I know in every finger, toe and split end that widespread acceptance [of PAD] will result in further abuse."

Yablick points to how easily health professionals can encourage someone to die. "The way I see this playing out if PAD is added to the mix is that, in the midst of an outburst, some disinhibited pain-in-the-ass substance-abusing patient exclaims, 'I'd just rather be dead!' He suddenly gets the individual attention he's been craving in this understaffed pit, and is lovingly coached to his rightful place.

"The law has to be crafted for the most vulnerable members of society," Yablick reminds us. "The law is for everybody. How can we support hastened death under these circumstances? It's a choice I want available for me and for everyone I love, but it's just too damn costly."

### Personal Redux

The law is for everybody. Viewed through that framework, some of the pieces shift into place and some go skittering off the puzzle board. What you make of PAD is your business, but here's where I landed after I made it mine:

After all the discussion, suicide remains a personal matter. Individuals, not organizations, commit suicide. We shouldn't moralize or psychologize after the fact.

Suicide aided by laypeople who provide knowledge and support--Hemlock's sort of assistance--raises the ante. More people participate and coercion, by others or by circumstance, becomes a greater concern. Yet Hemlock and other programs like it provide an alternative to PAD, and perhaps a better one. They enable facing death peacefully in the home, after the goodbyes are said, with friends and family present.

If we really want the option of hastening death, and if Hemlock were to drop its advocacy for PAD and concentrate on what it already does--take the P out of PAD--I'd be tempted to say it's the best way we can provide some autonomy in end-of-life decisions without opening the door to systemic abuse.

True, utilizing Hemlock's help can send a terrible message about disability, but it's a gentler message than legalizing PAD. And what message do we send if we allow ourselves to linger through intractable pain, dementia, through it all, whatever we've got, into nothing? Won't people say, "I wouldn't want to die that way"? Is it so bad to end a good life with a good death?

PAD is an enormous escalation from suicide, either solitary or in the company of others. It makes our end-of-life choices the province of law, medicine and economics, as implemented by a deeply flawed health-care system. My fear is that PAD will become a constant presence in health-care settings, a big friendly mutt that

lays its head in our laps and wags its lethal invitation whenever we doubt our ability to go on.

Readers with long memories may recall that I've been kinder to PAD in the past. I said I wanted the option available for myself and couldn't bring myself to distrust my doctors or hospitals. I feel the same now, but was wrong to think my preference was relevant to PAD legislation. It's relevant only to me.

NDY's arguments do seem relevant. They no longer strike me as paranoid and shrill, but as reasoned reflections of horrors already seen. With all my faith in my health-care providers, I have seen them. And NDY, more than other organizations, addresses the complexity of the issue.

AUTONOMY's arguments are tight, attractive and easy to grasp. That's its strength and its weakness--all its philosophical eggs in one basket. Personal autonomy is a worthy goal, but it's only one factor in lawmaking and, for that matter, disability rights. It offers no guarantee of benefit to society.

In the diffuse light of complexity, I see PAD inviting excess--eugenics resurrected by fetal DNA testing, for example, or Nitschke's vision of one-way euthanasia cruises, burial at sea included. Kevorkian's posturing as a savior. Peter Singer's promotion of infanticide for disabled newborns.

I'm left with too many inconsistencies that smell fishy. Why limit PAD to people who are terminal? Don't the nonterminal suffer? Why is PAD wrong in the presence of depression? Is it not part of the suffering that needs relief, and must we disqualify anyone whose depression cannot be cured? Why a waiting period for PAD requests? Whose asses and assets are we covering? Why offer PAD to people who are physically capable of taking their own lethal dose, and deny it to those who are not? Why aren't we better at the long-term and palliative care that might make PAD less attractive? Why do we "respect" the suicidal wishes of disabled people, yet treat the same wishes of nondisabled people as cries for help? Why would we make trusted doctors speed our passage to eternity? Why do so many people want PAD only because they're afraid of becoming like us?

There are good answers to some of these questions. But until they all, and many more, are part of the debate, we don't understand the issue.

There may come a time when PAD will make sense in this country. I cautiously hope so. But PAD now? I don't think so.