

A PIECE OF MY MIND

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Beliefs

Somehow, as a kid growing up in a nonreligious family, I developed a very strong sense of right and wrong, of what ethical and moral behavior should be. I have tried to follow this tenet throughout my life. When I became involved with medicine, I took to heart all the maxims we were taught, particularly "First, do no harm." But for many years now I have realized that this concept is wrong, dead wrong.

I believe that our first duty as physicians is to relieve pain and suffering, whether it be physical or emotional. Only then, secondarily, are we to avoid harming the patient. I say this because, as a neurologist and clinical neurophysiologist, I spent a great part of my practice causing pain and suffering in my patients, on purpose.

I have performed painful electromyograms and nerve conduction studies in patients, some of whom had to stop the procedures because they could not tolerate the discomfort. I have irrigated ears to make patients vertiginous, sometimes to the point of their vomiting. I have ordered painful or dangerous diagnostic tests. The worst, before modern imaging, was the pneumoencephalogram, a truly horrific thing for any person to undergo. Arteriography occasionally resulted in catastrophic strokes. I still remember a young actor with a small subarachnoid bleed who emerged with a severe aphasia and a normal study.

I have ordered medications with, at times, seriously uncomfortable or dangerous side effects. I have recommended operations that potentially could leave patients much worse off than they were. I have caused emotional distress by discussing brain death diagnoses, terminal illness prognoses, end-of-life issues that needed addressing (ie, a young father in denial whom I literally bullied into writing a will before he would become incompetent from his glioblastoma), limitation of driving or solo living for patients with dementia, and so on.

I have done all these things because I believed it was in each patient's best interests, to discover the cause of their problem or to alleviate their suffering, whatever form it took. These were my primary overriding concerns in all cases. First to diagnose and treat. Then, secondarily, to try to cause no unnecessary harm. The "unnecessary" being the key—synonymous with unwarranted, unjustified, inappropriate, and, if I may, merciless.

Now for the gist of where this is going. I believe wholeheartedly in assisted death. Not assisted suicide for depression. Depression is a treatable, reversible condition. Suicide is inappropriate, except in untreatable, unbearable suffering. Death is not treatable or preventable. Death can be easy or it can be utterly, devastatingly miserable. It can be totally destructive of all dignity, privacy, and autonomy, much less comfort. We have all seen it.

For years I practiced in a state where, if someone thought you were administering too much pain medication to a terminally ill patient and the patient died, you could be charged with and possibly convicted of murder. No amount of suffering was felt justified to intervene with "natural" death.

I personally have never met an individual who truly believed this on a rational, reasoned basis. In those who have professed this conviction, once the superficial logic had been taken away, it was always, at root, based on religious conviction. As such it has always been impervious to true discussion.

I fully respect the right of individuals to their own beliefs and end-of-life wishes. I do not condone the imposition of personal religious beliefs on someone who does not share the same convictions. I believe it to be morally, ethically, humanely, and mercifully unconscionable that a dying person must accept prolonged suffering if that individual does not wish it. Yet this is the law in 47 of the United States [at the time of this writing]—and the official position of the American Medical Association. This sometimes is justified by the myth that physical and emotional suffering at the end of life can be controlled. We all know that this is often not possible. Sometimes we resort finally to medicating the individual into a semiconscious state. And just what is the point of that? Most, supposedly rational reasons against assisted death are based on the "slippery slope" concept, that it opens the door to abuse and willful murder and then eventually to euthanasia. This ignores the ability of people of intelligence and good will to write appropriate guidelines and laws to protect against such actions. Some of these people crafted the Oregon Death With Dignity Act. In this act, passed by statewide vote in 1994 and repassed and enacted in 1997, an adult Oregon state resident with a diagnosed illness confirmed by two physicians as likely to be terminal within 6 months, who is found to be mentally competent and not significantly depressed (by consultation if necessary), may be written a prescription for a lethal amount of an oral medication, which must be self-administered. Statistical, demographic, and medical data have been collected on the people who have received such prescriptions since 1997.¹

Obviously there is a personal issue. Two months ago I was diagnosed with advanced myelodysplastic syndrome. My estimated survival time is 4 to 6 months, which I suspect is optimistic. At my age, 73, and general medical condition, bone marrow transplant is not an option. Chemotherapy might offer a few months of extended existence, at the risk of spending it all sick from adverse effects. I have opted for palliative care in hospice. I will eventually die of anemia or infection of some sort. And there is the rub. What sort of death will it be? I personally opt for as easy as possible.

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By easy I mean free of pain, diarrhea, nausea, vomiting, incontinence, delirium, dyspnea, anxiety, and loss of autonomy, mobility, dignity, mental clarity, and the ability to enjoy any of the pleasures of life—make up your own list from your own experience. I also include being free of concern over the effects of my condition and need for care on my loved ones.

I feel very lucky, right now, to live in Oregon. I have completed the three-week approval procedure required under the Death With Dignity Act. I have done this because it gives me great peace of mind. The alternatives to legal assisted death are not particularly appealing: starvation, dehydration,² or active suicide—all of which can be unpredictable, unpleasant, uncomfortable, and terribly distressing to family—and which also expose them to charges and possible legal action for abuse or murder.

Please remember: to cause no “unreasonable” harm is the appropriate approach to medicine in general and most specifically to the end of life. Consider your own wishes for yourself and family. You may not wish to think of it, but do ponder: if you knew you were dying soon, how would you want to die, if you had the choice?

If you disagree with these concepts, and I am sure many do, please consider whether your first duty should be to truly relieve the

pain and suffering of your patient, who wishes it, or to your personal religious preference. We are not “healers.” We almost never truly heal a patient of a serious disease, certainly not death. We are “treaters” who should try to help each individual patient deal with his or her problem to the best of our ability. Sometimes, for a dying patient, the option of an easy, assisted death is the most merciful, caring, and, I believe, ethical way to do that. I personally also believe that if a person knows he is dying, he should not be forced to wait until the unpleasantness actually begins. As in Oregon, he should be given the opportunity to die at his own time of choice. I personally choose to die before becoming bedridden or infection sets in, after I have tied up my loose ends and made the transition as easy as possible for my wife and family (who are in entire agreement with my actions).

If you agree with these ideas, consider asking your own state to join Oregon, Washington, and Vermont (since it is a states’ rights issue) in giving those men and women who want it the choice of how they wish to die. Consider urging the AMA to reevaluate its position on physician-assisted death in its Code of Medical Ethics.³ This truly is a test of personal autonomy and freedom of belief.

Editorial Note: Dr Rowe died November 11, 2014, in Medford, Oregon, with the aid of the Oregon Death With Dignity Act.

1. Death With Dignity Act. Oregon Health Authority. <http://public.health.oregon.gov>

[/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx](http://ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx). Accessed June 22, 2015.

2. Eddy DM. A conversation with my mother [A Piece of My Mind]. *JAMA*. 1994;272(3):179-181.

3. American Medical Association. Opinion 2.211—Physician-Assisted Suicide. <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2211.page?>