



3855 Telluride Place
Boulder, CO 80305
303 499 8120

Bart@AxiomAction.com
www.AxiomAction.com

Dying in Peace Requires Citizen Ownership and Marketplace Transparency by Bart Windrum, August 2013

An Open Letter to the Institute of Medicine's Committee on Approaching Death, to the medical community, policymakers, and my fellow citizens.

Abstract *We all say that we want to die in peace. Several unspoken root causes undermine peaceful dying: the ownership of dying assumed by medicine, and an opaque end-of-life marketplace where provider (both institutional and individual) orientation around end-of-life treatment and ethics is not revealed until after the dying and their families have come under provider control as (in)patients. The Committee's forthcoming report about how to increase the likelihood of peaceful dying on a national scale must include recommendations to overcome these impediments because they are fundamental issues rarely, if ever, addressed.*

Dear 2013 IOM Committee on Approaching Death members:

After experiencing my parents' respective three-week terminal hospitalizations (Ruth Greenberg, January 2004, intubated/comatose/ICU; and Morton Greenberg, April-May 2005, fatal nosocomial MRSA), I fell into a quest to unearth and understand all the failures contributing to non-peaceful dying: my failures, my family's failures, medicine's failures, and society's failures. Call it a citizen's root cause analysis. This quest has led me to produce several books, a state initiative (unadopted), and more recently an end-of life rap, a groundbreaking thanatological work, and a TEDx talk (reference links below).

Early on I recognized that each of us—not medicine—bears primary responsibility for dying in peace. Nine years later, I have come to realize that an opaque end-of-life (EOL) marketplace fundamentally impedes people from experiencing a peaceful demise.

I've been listening carefully to what medicine has said during these years. What medicine does not say speaks most loudly, and it has failed to address these two issues. The Committee's scope, mission, and report ought to include comments and direction regarding both individuals' ownership of dying and advance transparency by institutional and individual medical providers.

Earlier this year I forwarded you a document summarizing Windrum's Matrix of Dying Terms™. Windrum's Matrix attempts to solve a fundamental obstacle to dying in peace by using simple, neutral language to clarify a heretofore undifferentiated continuum. By failing to differentiate in advance among dying outcomes, that is, the situations we find ourselves in during a demise, people remain clueless about how complicated 21st century dying has become. Windrum's Matrix



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expands the sole term “dying,” which fails to forecast or describe the range of dying experiences ahead of everyone in the developed world. The Matrix, perhaps for the first time, identifies and names sixteen distinctly different dying outcomes, each with a neutral, descriptive prefix to the word “dying.” Each name takes its meaning from the combined effect of who or what controls dying and the time elapsed from the onset of terminality to death. This clear set of names helps us assess, in advance and more specifically than advance directives alone, the type of dying experiences we want to aim for and also to avoid.

I view Windrum’s Matrix—developed last fall (2012)—as a baseline, because it gives us the language to distinguish among an otherwise indistinct sense of the wrong places most of us land (where “wrong” means not dying peacefully despite a stated desire to; and where “peacefully” refers to the situations we find ourselves in over time as we die).

The idea of dying in peace—often stated, rarely achieved—sits atop two foundational ideas that I do not hear discussed: who owns and controls dying, and opacity in the dying marketplace.

Below, for your consideration, I delve into these two rarely discussed requirements for peaceful dying. I hope that you accept these as fundamentals and address them in your forthcoming report. In a re-visioned end-of-life landscape:

1. In their public commentary, medical establishments, departments, doctors, and nurses must push back the primary responsibility for dying to the public
2. Medical establishments, departments, doctors, and nurses must transparently declare in advance the type and range of end-of-life treatment each offers.

In their public commentary, medical establishments, departments, doctors, and nurses must push back the primary responsibility for dying to the public

I believe that providers offering end-of-life treatment intend to do good and right. I begin with this acknowledgement because my points below have the potential to offend, which is not my intent. I vowed in 2004 to get to the bottom of our failures, and this is one place that my vow takes me.

Behind most current EOL initiatives from advance directives to palliation lays the idea that, ultimately, medicine controls and bears responsibility for our dying. I have never read or heard an explicit statement from providers to the public saying, in effect, “Hey, we’re here to help, but you’re asking too much of us and it’s time for you to take personal responsibility for orienting yourselves toward peaceful dying...so please study up—learn to identify and manage 21st century obstacles to achieving the deaths you say you want.”



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When we end up under end-of-life medical treatment—an almost universal circumstance given the predominance of medically-managed dying—we also end up under medical control. Yes, advance directives seek to shift control over dying to dying people. As important as advance directives are they do not eliminate, and in many cases insufficiently mitigate, the range of obstacles to peaceful dying (acquiring the skills to do so is a long-term studious undertaking). The fact that legal documents have become required to attempt to control the situations within which we die reveals how central the issue of control has become to dying in peace—so much so that it ought to be put on the table very distinctly.

Attempting to compensate for the pervasive denial of death, providers try to solve everyone's EOL problem. Individual, social, and medical denial leaves providers "holding the bag." When the dying present, unprepared, in a medical environment, medicine does what it can. Over time, doing what one can becomes doing what one wants, and that gets entrenched, systematized. Eventually, a sense of ownership takes root. It's time for medicine to do what must be done: tell the citizenry to do serious homework around dying in peace...that medicine is not, fundamentally, responsible for dying in peace. And then to relinquish control.

This will require medicine to give up its sense of ownership over dying and offer itself as a helping hand, perhaps companion. Helping, accompanying—these are not roles of control or ownership. They are, at best, roles of co-creation. This does not mean that medicine ought to abandon programs such as advance directives and palliative treatment; these should be further refined. Rather, the public will be better prepared over time to embark upon dying when people understand that the primary responsibility for how they end their lives is, in fact, theirs.

I believe that your committee must acknowledge this aspect of 21st century dying or be guilty of perpetuating the unspoken idea that medicine owns dying. I submit that the palliative and hospice worlds are not immune to this orientation and that their growing visibility do not and will not intrinsically solve the problem. As e-Patient Dave deBronkart says, "let patients help." Society requires a nudge from medicine about this, to get its end-of-life act together before it's too late to course-correct any given non-peaceful demise.

Medical establishments, departments, doctors, and nurses must transparently declare in advance the type and range of end-of-life treatment each offers.

I've refreshed the Committee's memory of Windrum's Matrix because the Matrix has helped me to explicitly understand the range of dying outcomes it identifies as service levels in the dying marketplace. The Matrix has allowed me to sense what's ever-present yet unacknowledged in both public and medical discourse about dying: that our dying marketplace is opaque.



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It may seem strange to speak of dying in commercial terms. Doing so may go against the grain of those who see their work primarily as a calling. Doing so may offend the sensibilities of those who believe in contemplative practice as the primary means to peaceful dying regardless of the array of obstacles against that in our technological, legalized, and medicalized culture. Yet we cannot deny that an end-of-life marketplace exists and that medically-managed dying—society’s predominant dying experience—is purchased. No matter where dying’s management falls on the continuum from quick to protracted dying, money is exchanged for services rendered.

Today we are seeing the nascent development of a movement for healthcare pricing transparency. Dying in peace desperately requires a similar movement: for service provision transparency.

Today, no one talks because we are afraid of being identified according to our stance on the range of dying options and treatment ethics. We’re afraid of acknowledging mortality and of exposing ourselves to judgement and/or ridicule, to legal liability and pursuit. But dying in peace requires that everyone identify what they’re seeking/buying and what they’re offering/selling—in advance of terminality or, to put it in commercial terms, before entering into a dying arrangement.

Currently, no one—neither citizens or providers—know each others’ orientation around EOL treatment and ethics until after we become customers/patients. Citizens buy dying sight unseen. Only after people present and become terminal do providers, cautiously and with great trepidation, reveal how they view dying, their dying services, and their ethics regarding how death unfolds and occurs. As an analogy, it’s as if institutions and providers don’t reveal their dying “menus” until after people have been seated, dinner is served, we’re deep into the meal, everyone (both diners and servers) are subject to indigestion, and the diners are indebted for all the costs. That’s too late for peaceful dying. (Here, please remember that I’ve experienced each of my parents’ three-week terminal hospitalizations, and that both were completely non-peaceful experiences, in ways large and small, from start to finish—and we didn’t do better the second time because the medical courses were so different from one another that the first death, Mom’s, didn’t provide definitive guidance to overcome obstacles encountered during the second death, Dad’s.)

Opacity and obfuscation regarding how one intends to treat the dying is absurd. It’s inhumane. This situation persists due to fear of disclosure. Yet identifying one’s position regarding the dying continuum is the only ethical action. Doing so is not illegal.

Transparency can and will relieve provider and citizen stress. Imagine a transparent dying marketplace in which patient-families know in advance and may select from among the range of services offered. Imagine a dying marketplace in which providers can reasonably expect that their



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patient-customers will self-select based on provider disclosure. What harmony: dying people seeking and buying medically managed dying services based on shared values!

Institutions, departments, and providers: what kind of dying services do you offer? Essentially the continuum includes:

- Never-ending dying: we won't mention dying; we will keep you going as long as possible using every means available up to and including persistent vegetative state, for as long as doing so is desired, legal and paid for.
- Mainstream dying: we forestall dying throughout the full duration of a disease course.
- Conservative palliative dying: we medically manage dying, conservatively applying palliation.
- Aggressive palliative dying: we medically manage dying and rigorously apply palliation to forestall protracted dying to the fullest extent allowable by law.
- Assisted dying: where legal, we offer aid in dying.

There is no shame in providers proclaiming their orientation on this continuum of dying services. I see only benefit and peace for everybody. Of course it's easy to imagine objections, centered around provider liability should someone's loved one die at a time or in a manner a family member finds objectionable. To which I say, for example, that the purchase of aggressive palliation might require that a release be signed—or perhaps and future-oriented, the development of tests that would determine on an individual basis the amount of palliative medicine any one of us could absorb without inadvertently being overmedicated to death.

Conclusion

Most of the 2.5 million dying Americans each year and their families experience far too much unnecessary emotional and psychological pain around dying because our system makes dying harder than necessary. The unwarranted assumption of ownership of dying coupled with opacity in the end-of-life medical treatment marketplace plus silence from all quarters contribute to that pain. Isn't dying intrinsically painful enough without us willfully contributing more? That's the disease we need first to palliate. Delayed palliation of the pain resulting from these conditions is not a zero-sum game. The pain accumulates for the dying, their families, and providers. Personally waiting too long to understand ownership and control over dying, revealing a professional orientation and "menu" of dying services later in the dying process—these actions, while better late than never, do not mitigate the accumulated pain. Too many of us have and are haunted by stories of deaths we'd hoped might be peaceful and that instead were excruciating to experience and which remain so in memory. This situation adds stress to every participant's life, both lay and provider.



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IOM Committee: begin the process of transferring ownership of, responsibility for, and control over dying to the citizenry. Suggest that medicine forthrightly say that it can not and ought not do for people what we must do for ourselves. Reinforce that by instructing providers and the public alike to come out of the shadows. Medicine: clearly articulate what you will and will not offer the dying. People: after learning to identify and overcome the many obstacles to dying in peace, say what you want. Ask providers exactly what range of dying services they offer. Let like seek like.

Thank you for considering the points I've raised. By illuminating these matters in your report you can jumpstart a foundational conversation that will help each of the 2.5 million Americans who die annually to die in, and therefore at, peace.

Bart Windrum, author/speaker

Reference—links to Bart Windrum's end-of-life works:

- Notes from the Waiting Room: Managing a Loved One's (End of Life) Hospitalization 2008, Axiom Action, www.AxiomAction.com/notes-from-the-waiting-room
- How to Efficiently Settle the Family Estate 2008, Axiom Action, www.AxiomAction.com/efficiently-settle-the-family-estate
- The Option to Die in PEACE (Patient Ethical Alternative Care Elective) viewable at <http://www.colorado.gov/cs/Satellite/BlueRibbon/RIBB/1176241324570>
- Windrum's Never Say Die Rap, www.AxiomAction.com/rap
- Windrum's Matrix of Dying Terms™, www.AxiomAction.com/matrix
- Dying IN Peace to Die AT Peace: New Terms of Engagement, TEDxFoCo3, May 5, 2013 <http://tedxtalks.ted.com/video/Dying-IN-Peace-to-Die-AT-Peace;search%3Abart%20windrum>