

Summary: The Option to Die in PEACE (Patient Ethical Alternative Care Elective)
from *Notes From the Waiting Room: Managing a Loved One's End of Life Hospitalization*
by Bart Windrum, Boulder CO 2009

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The Option to Die in PEACE (Patient Ethical Alternative Care Elective) is a sociopolitical proposal to help Coloradans and Americans achieve the peaceful demise 90% of us say we want (and roughly 15% of us achieve). PEACE represents a paradigm shift in how we approach dying.

Statistics

- 90% of Americans say they want to die in peace, at home
- 50% die in hospitals (places ill-equipped to care for the dying)
- 20% die in nursing homes
- of those who use hospice, 35-50% are hospice patients for 4 days—generally corresponding to the very last life phase known as active dying. These patient-families under-utilize hospice and hospice services. We may surmise that their brief period of active dying has been preceded by days, weeks, or months of demise; thus adding 10-15 percentage points to the numbers of Americans dying in hospitals and nursing homes.
- assuming a 3-week terminal hospitalization and an 85-year lifespan, that last, tumultuous, expensive phase represents 7/10,000 of a lifespan.

About *Notes from the Waiting Room*

Notes From the Waiting Room: Managing a Loved One's End of Life Hospitalization fills several roles. For lay readers, *Notes* is at heart an instructional manual for managing any hospitalization. *Notes* also helps us consider how to approach and make the choice to opt out of institutionalized dying—how to *manifest one's resolve* to die peacefully (the social component of PEACE). For providers, I describe *Notes* as a lay person's root cause analysis into systemic failures resulting in harm and adverse outcomes for patient-families. For policy makers, *Notes* offers a number of reform initiatives. *Notes'* sociopolitical discussion of PEACE is given its own chapter.

Social PEACE: Individuals, Families, and Society Need Lead-Time to Come to Grips With Dying

Our preference to die peacefully is often derailed; although we say we want peace, we choose what often turns out to be its opposite: institutionalized dying. *Notes* explores the reasons why. Among the reasons are denial of death, unquestioned calls to 911, hospital admissions and their associated tolls, ignorance of how the system functions, almost ceaseless acute curative treatment in the face of death, and other systemic defaults and problems (largely an extensive lack of effective communication and guidance when we're hospitalized and/or dying). Lay persons and providers share responsibility for these conditions and their outcome.

Patient-families need lead-time to begin to come to grips with end of life. We need to understand the risks associated with every hospitalization (all the risks: medical, existential, emotional, spiritual, financial, cultural, legal).

We also need an introduction to, a better understanding of, and familiarity with the benefits of hospice as an enabling service for the peaceful demise almost all of us want.

Lead time is required to gradually foster understanding and acceptance of hospice/palliative care as a viable end-of-life pathway. The Option to Die in PEACE proposes a paradigm shift in hospice eligibility to obtain that lead time.

Political PEACE: Hospice Changes Can Help Provide the Lead Time, at Reduced Cost

Hospice would like the current eligibility requirement of six months' terminal diagnosis changed to 12 months. I propose changing the requirement from a hard standard (beyond the shadow of a doubt) to a softer standard: *by a preponderance of the evidence*. (Note: doctors' application of the six month standard is wrong with some frequency, and that ideal "six month's left to live" can and does shrink to as little as two weeks.)

Our typical late-life scenario is to benefit from good medicine and live for years or decades with multiple, increasingly severe and interrelated ailments. When a turning point comes we often don't recognize its literally grave importance, because we don't know that turning points are exactly what causes death's onset.

At some point during these years we begin the long decline. That's the moment we want to assess: the change from ascendance to decline. PEACE proposes a new clinical evaluation for when we turn the corner from living with what ails us to dying from what ails us—at which point we become eligible for a new breed of hospice services, perhaps several years before dying.

The new hospice services would begin with a simple "ticket to ride"—eligible citizens will be enrolled by default. New enrollees get a welcome packet. Foremost, it explains that enrollment is passive and activation/utilization is optional. The packet further briefs new enrollees about hospice/palliative care: the statistics, the potential evidence-based benefits for outcomes and longevity, personal/social dollar costs, and whatever else is deemed appropriate to convey.

Service options and delivery would expand as medical conditions worsen and life conditions indicate. The new expanded hospice benefit would include a range of services that naturally accrue to dying. Provider-reimbursable services would include consultation and support for the patient-family including family-member caregivers, activities of daily living, as well as acute medical support. Providers would be reimbursed for consultation and guidance-counselling that naturally accrue to long-range end-of-life planning and realities.

I believe that this new hospice environment would help to start and maintain a statewide and national conversation about humane and economical dying—*in enough time for Americans to come to grips with, explore, agree to, and manifest a more peaceful (some would say sane) and economical demise*. Policy makers can change policy *and also change behavior through positive inducements*, rather than simply making policy and letting society figure out how to deal with it. This approach fulfills the Colorado's stated goals around educating its citizenry, and applies compassionately to potentially concerning policy change.

Social PEACE: Manifesting the Resolve to Die Peacefully

Coming to the personal decision to forego what could turn into a last, terminal hospitalization is a profound process. None of us know how we'll respond to medical and moral crises in the moment, the most trying and vulnerable times of our lives. My multiple-award-winning book, *Notes From the Waiting Room: Managing a Loved One's End of Life Hospitalization*, addresses these matters. This citizen-author stands ready to engage anyone and everyone in the conversation. I speak to lay and professional audiences nationally, and welcome any opportunity to speak and testify going forward.

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Bart Windrum

Lay Person Author, Speaker, Citizen-Advocate

Unique Guidance from the Patient-Family Experience

- Managing Hospitalization
- Settling the Family Estate

Bart Windrum, a lay person, acted as both Medical and Financial Power of Attorney during the demise of each of his parents in 2004 and 2005. Multiple disturbing and harmful experiences during those times prompted Bart to examine, research, and clarify the nature of hospitalized dying in America *from the patient-family experience and perspective*. This perspective offers a unique contribution to American families.

(End-of-life) Hospitalization: In *Notes from the Waiting Room*, Bart dissects and clarifies hospitalization experiences. He also discusses end-of-life choices, broaching the thorniest issues—from the patient-family viewpoint. Illuminating and empowering for every patient-family, entering any hospitalization or end-of-life crucible.

Estate Settlement: Bart provides real-world guidance for efficient estate settlement in the same no-nonsense, personal, humane manner as for end-of-life matters.

In the course of writing *Notes from the Waiting Room*, Bart authored **The Option to Die in PEACE (Patient Ethical Alternative Care Elective)**, one of thirty-one healthcare initiatives accepted by Colorado's Blue Ribbon Commission for Healthcare Reform.



Citizen-Author-Expert and End-of-Life Reformer

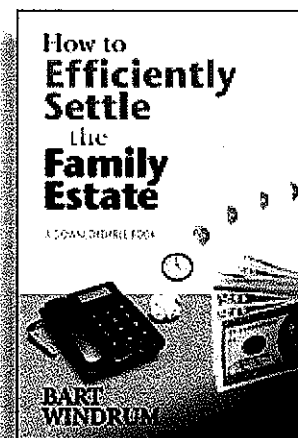
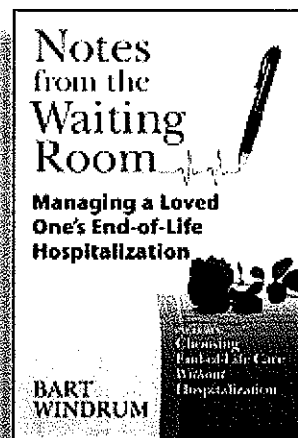
- For Lay Persons and Pros
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The Unique Power of a Citizen-Author-Expert. One vitally important voice is missing from public healthcare and policy conversations: the citizen-expert.

Citizens who have endured and examined tough experiences, and faced ultimate choices, can give the conversation practical immediacy for fellow citizens—from individuals and families to providers, organizations, and institutions.

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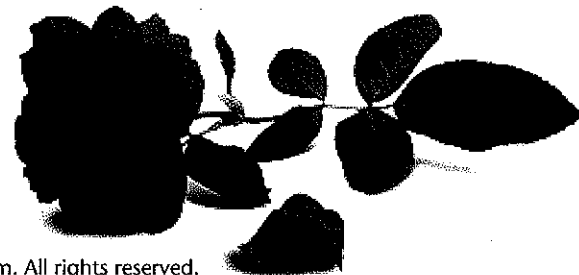
- Managing (end-of-life) hospitalization
- Manifesting the resolve to die in peace
- Patient advocacy guidance for women in their second half of life
- Enhancing hospice community outreach
- The Complete Do Not Resuscitate Conversation
- Efficient estate settlement for survivors
- Also, *the one-of-a-kind*
- Citizen-Author-Expert Hospitalization Panel



Flip the page for presentation descriptions, reader comments, and catalog data.



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Bart Windrum Speaks About...

Managing (End of Life) Hospitalizations The medical world urges us to have an advocate accompany us during any hospitalization. Learn how to function in this role to minimize harmful shock during the most vulnerable times.

Manifesting the Resolve to Die in Peace 90% of Americans say they want to die in peace. 75% experience an institutionalized demise. Learn what must we know in our minds and hearts to manifest the peaceful end of life we want.

Patient Advocacy Guidance for Women in their Second Half of Life Chances are that women will fill the role of patient advocate. Learn what is imperative and vital in order to act successfully on your loved one's behalf in the hospital.

The Complete Do-Not-Resuscitate Conversation A living will is the exposed tip of the ethical iceberg waiting below the surface of any hospitalization. Explore the full range of issues at the intersection of patient directives, the treatment plan, resuscitation technology, and provider prerogative.

The Citizen-Author-Expert Hospitalization Panel Engage with several citizen-authors. There's nothing quite like straight talk from informed and experienced citizens.

A Few of the Events Bart has presented at:

- Hospital Corp of America Annual Ethics Conference, Nashville TN (keynoter)
- Colorado Center for Hospice and Palliative Care Annual Conference, Breckenridge Colorado

Praise for *Notes from the Waiting Room*

A practical, wise, and timely exploration of an inescapable universal event. This book speaks to us all. *Richard D. Lamm, former three-term Colorado Governor*

Notes from the Waiting Room offers a poignant and elegant examination of tensions interfering with the peaceful demise most Americans say they want. Constructive, engaging, and challenging...a must-read for laypersons and professionals who champion common sense, good stewardship, and humane caring. *Diann Uustal, RN, MS, EdD; Clinical Ethicist, Palliative Care and End-of-Life Consultant.*

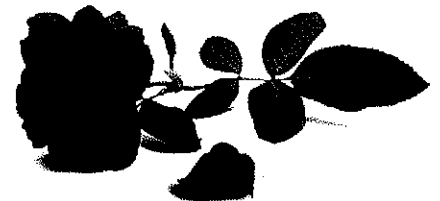
Notes from the Waiting Room distinguishes Bart Windrum as a thought-provoking author who has opened new discourse about end-stage medical care. His balanced presentation and practical analysis lay a foundation for finding direction at the most difficult moments. *Jane Mountain, MD, Author*

The Option to Die in PEACE (Patient Ethical Alternative Care Elective) is of great benefit to patients and families everywhere, providing a practical framework to master a maze of conflicting options and opinions. *Robert Eaton, Director of Mission and Spiritual Care, Office of Mission and Ministry, St. Anthony Central Hospital, Denver, Colorado*

I finished this superb book with tears in my eyes, a smile on my lips, and thanks for all this author has given us. *Notes from the Waiting Room* has motivated me to finally attend to our end-of-life responsibilities, so my survivors' load may be as light as possible when I pass on. *Carol Sheer*

Notes from the Waiting Room will prepare you to navigate complex medical and legal systems...and equip you to be an effective patient advocate through some of life's most challenging circumstances. ...Mr. Windrum has provided a compass for you to expect the unexpected and become an effective advocate for those you love. *Cordt T. Kassner, PhD; CEO Colorado Center for Hospice and Palliative Care*

Appreciation for *How To Efficiently Settle the Family Estate* In our hurry-up, "just give me the facts" world, we may not expect much from how-to books beyond topicality and organization. We have forgotten how good the best helpful compendiums can be. I know: I edit them...Bart Windrum brings a personal touch and humanity to this somber and often technical topic. His humor and evident caring lighten the informational load. *Barbara Munson, Munson Communications*



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