

A Proposal to the Colorado Blue Ribbon Commission for Health Care Reform:

The Option to Die in PEACE
(Patient Ethical Alternative Care Elective)

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The Option to Die in PEACE (Patient Ethical Alternative Care Elective). From the forthcoming book *Notes from the Waiting Room: Managing a Loved One's End-of-Life Hospitalization*, by Bart Windrum.
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a) Comprehensiveness

(1) What problem does this proposal address?

NOTES:

1. *Terms like “people”, “all people”, “everyone” and similar terms within this proposal refer to people in Colorado.*
2. *This proposal refers to and contains concepts and terms appearing within a book authored by Bart Windrum and currently in pre-publication, regarding how to effectively manage a loved one’s hospitalization, especially one that begins as or becomes terminal.*

The Option to Die in PEACE (Patient Ethical Alternative Care Elective) addresses a range of interrelated problems that afflict many, if not most, people who die an institutionalized death, specifically those who die in hospitals or whose dying process occurs primarily in hospitals. For our purposes regarding this proposal, dying in the hospital means enduring a last hospitalization that either begins as or becomes a terminal hospitalization, where the patient stays hospitalized up to and including the time of death, or to within several days of dying, no matter where death subsequently occurs. Current literature estimates that between 50-75%¹ of Americans die institutionalized deaths, with the predominant number of these occurring in hospitals (distinct from nursing homes).

The problem of hospitalized dying includes:

- subjecting patients and their families including a designated medical agent / power of attorney (hereafter referred to as the *patient-family*) to the angst associated with institutionalization and institutionalized dying—due primarily to the way the system treats patient-families (“system” refers to hospitals as institutions and individual treatment providers, both independent of and employed by hospitals)

¹ Last Rights: Rescuing the End of Life from the Medical System, Stephen Kiernan, St. Martin’s Press, 2006 and Reclaiming the End of Life, Ira Byock MD, www.ReclaimTheEnd.org

- the financial cost of extended hospitalizations and their expensive interventions to insurers, individuals, families, and ultimately society, multiplied by the number of individuals dying in hospitals
- the delivery, according to one's viewpoint, of less than optimal care during end of life when compared to what's possible at less cost, less disruption, and with compassion adequate to the circumstances outside the hospital setting.

(2) What are the objectives of your proposal?

The objectives of the Patient Ethical Alternative Care Elective (hereinafter referred to as *PEACE*) are to introduce, legislatively sanction, publicize, make available, and subsidize an end of life option that all Coloradans could utilize at their sole discretion. Specific objectives include:

1. *launch a public awareness-raising campaign* regarding a) the existence of the hospice option b) an explanation of what hospice is and is not; and c) begin a societal conversation about dying and death, its place in the cycle of life, and ways in which independent Coloradans might approach dying and death
2. *guarantee everyone an option to arrange their demise* outside the bounds of hospitalization or other institutionalization
3. *guarantee adequate pain relief* throughout the course of one's demise
4. *empower patient-families to take control* over their loved one's demise
5. *allow certain treatments currently categorized as "curative"* to be continued within PEACE when such treatments have a primarily palliative effect that enhances quality of life remaining
6. *amend the Colorado statutes for physician licensure* to include a requirement for significant course-hours and subsequent ongoing training in palliative and end of life treatment and care.

b) General

(1) Please describe your proposal in detail.

BACKGROUND

PEACE is the logical outgrowth of a two-year investigation into why the experience of terminal hospitalization is what it is in America. The investigation resulted from my personal experience during each of my parents' deaths. Former Colorado residents, they each died in Florida, in different institutions under very different circumstances. During my mother's death in 2004 I was part of the patient-family, both an affected adult child and a primary support to my then 83-year-old father. During my father's death in 2005 I took on the additional roles of medical agent and property agent / estate trustee.

These events were characterized by situations that are probably familiar to Commission members, including:

- discontinuity of care (“care” will be hereinafter referred to as *treatment*)
- the absence of a treatment lead as a go-to resource for the patient-family and all physicians and other treatment providers attending the patient-family (insofar as the family portion of the customer base is attended)
- an almost complete lack of advance guidance from two hospitals and all attending physicians as to procedural flow and timelines, and choice points and considerations (distinct from prognoses); I refer to this condition collectively as a lack of *forecasting*²
- antagonistic family policies in the ICU
- multiple instances of ethical gray zones related to patient resuscitation designation, categorization, and patient-family wishes—all of which could have been forecasted, none of

² The core, clinical definition of forecasting is attributed to Dr. Diann B. Uustal, RN, MS, Ed.D, Educational Resources in HealthCare. I extend that definition to include guidance to patient-family members about the entire range of hospital, illness, and treatment experience.

which were, each of which applied needless shock to the patient-family, one of which resulted in a life and death choice point leading directly to death, outside the bounds of heroic intervention

- the layering on of systemically-induced shocks beyond those inherent to the fact of a loved one hospitalized and dying, due directly to the lack of forecasting (hereinafter referred to as *extrinsic shock*)
- the irretrievable loss of opportunities to commune with and receive treatment directives directly from a dying loved one, due primarily to the above conditions.

After my second parent's death, I began an inquiry to establish whether my experience and developing theses might be extendable to the general population. I established that they are extendable and relevant to any citizen. Interviewees included professionals from the following disciplines and realms: nurses (hospital unit, hospice, Emergency Department, and private practice nurses), physicians (Emergency Department and private-practice doctors), patient representation (liaisons), Pastoral Care and Mission, medical bioethics, ethics committee, hospice administration, assisted living administration, and "plain folk." Additional source material includes current literature from medical anthropology and end of life / patient's rights advocates.

PROPOSAL

The Option to Die in PEACE consists of two platforms:

1. PEACE, the educational initiative. A low-tech, low-cost investment having the potential to change thousands of lives and result in significant dollar savings for patient-families whose dying bypasses distressing and costly hospitalizations that turn terminal
2. Changes to physician licensure. Palliative care, although specifically meaning to relieve pain (while not aiming to cure), seems to have morphed into a description of treatment that addresses patients as complete persons, distinct from this or that organ or bio-physical sub-system. Since modern end of life is typified by extended life leading

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ultimately to multiple frailty and organ failures near end-stage, the notion of palliative care has been expanded to refer to end of life treatment for the near-terminal and the dying. Physicians ought to be well- schooled. and acquire experience as interns in providing palliative care and in dealing straight on with end of life matters and the treatment of whole people rather than one or another bodily part or system.

PEACE proposes the following:

1. A state-sanctioned and produced public awareness campaign to inform Coloradans about alternatives for dying, specifically the federal Medicare Hospice Benefit, what it is, and what it isn't. 50% of hospice patients of a Denver area hospice are cared for by hospice for only *four days*³... meaning that their patient-family hospice experience comes at the tail end of the dying trajectory and process which preceded hospice intake. This scenario does not represent taking full advantage of the benefits hospice offers. Because people either don't know about hospice or misconstrue hospice care as hastening death, part of the campaign would be to frame a hospice choice as an decision regarding how one would prefer one's last phase of living unfold, rather than as a "death sentence."
2. A guarantee to any citizen of the option to arrange their demise outside of hospitalization—made possible through comprehensive advance knowledge of what hospice is and offers. Once one has entered a hospitalization that turns terminal it is often too late to regain control, dignity, acquire pain-management, remove oneself back to the home, and proceed to end of life without the systemic shocks and disruptions that are hallmarks of hospitalized dying.
3. A guarantee of pain-relief throughout the dying process that is adequate to the task and purpose. Colorado SB 102 has already been amended to protect medical caregivers from prosecution for prescribing effective doses of palliative medication to the terminally ill. There should be no reason or instance of inadequate pain relief for the terminally ill in any environment, hospital, other institution, or under the care of a hospice program

³ Hospice Executive Director personal interview given to Bart Windrum

whether at-home or in a hospice facility. Yet administering adequate pain relief continues to be a problematic aspect of medical treatment,⁴ especially in hospitals and even inside of hospice programs.

4. Empower people to take control over their demise by providing the information and framework required for them to understand the nature of dying and death alternatives, and how these options relate to their own family wishes and values.
5. Make certain allopathic treatments currently viewed as curative available to hospice patients when their primary effect is palliative, increasing the quality of remaining life rather than merely extending life or prolonging death
6. Amend physician licensure to include significant extended course-hours and subsequent ongoing training in palliative care and end of life patient-family treatment. A few brief course-hours in these topics sprinkled among years of medical training⁵ does not adequately prepare or orient physicians to deal compassionately with whole people to provide quality end of life care (distinct from bodily repair treatments). While there seems to be a budding national movement to provide integrated and palliative treatment, primarily from religiously-based hospitals⁶, I am hard-pressed to believe that any meaningful change can be effected outside of the way physicians are trained, and what physicians are trained—and licensed—to value.

(2) Who will benefit from this proposal? Who will be negatively affected by this proposal?

This proposal will benefit anyone wanting the option to die a more natural death, without the risk of undergoing (and subjecting their family members to) the suffering, indignities, and financial

⁴ Last Rights: Rescuing the End of Life from the Medical System, Stephen Kiernan, St. Martin's Press, 2006 and personal interviews given to Bart Windrum

⁵ Kiernan

⁶ Pastoral Department interviews given to Bart Windrum

toll that may accompany hospitalized dying—conditions which occur, in some measure, due to the nature of hospitalized deaths as time-managed⁷ according to insurance imperatives related to billable treatment.

This proposal will benefit service providers who may serve an emerging market of patient-families who opt to die at home.

This proposal will benefit physicians (assuming additional training and licensure) by making their day-to-day patient-family interactions more open and humane. Institutions will benefit by experiencing streamlined hospitalizations due to improved awareness of irrefutable human aspects of end of life circumstances.

This proposal may negatively impact physicians, institutions, and entities currently making money from customers who die hospitalized deaths.

(3) How will your proposal impact distinct populations (e.g. low-income, rural, immigrant, ethnic minority, disabled)?

PEACE's potential impact for all of us is huge—and equal. However, its potential may be special for members of ethnic minorities and the disenfranchised who come to understand how it benefits them (which is the same way it benefits any citizen regardless of their social station or resources).

Studies cited by a recent Washington Post article (*At the End of Life, a Racial Divide*, March 12, 2007) indicate that some minority citizens want aggressive end of life treatment due to cultural values and perceptions of having done without societal resources throughout their lives. With the

⁷ ...And a Time to Die: How American Hospitals Shape the End of Life, Sharon Kaufman, Scibner, 2005.

right educational component, it is possible that PEACE could help disenfranchised citizens understand that they could utilize PEACE services and resources while dying more comfortably; that utilizing aggressive end of life medical technology just because it's there and can be obtained may not serve their true interests.

Especially in regard to the disenfranchised, it is important to restate that PEACE is each individual's *elective*, and is neither a government mandate nor an individual imperative.

(4) Please provide any evidence regarding the success or failure of your approach.

I have direct evidence, corroborated by subsequent research, that hospitalized dying fails in ways that are deeply distressing, personally harmful, and expensive. It stands to reason that alternatives like PEACE can offer patient-families satisfying, possibly uplifting, and comparatively affordable experiences by removing the conditions that breed their opposite.

The failure of hospitalized dying can be exemplified by my parents' demises. In one instance, my mother died after almost 3 weeks of continuous intubation in an ICU; the gross bill was \$145,000. My father died after 2 to 3 weeks in a general unit; the gross bill was about \$85,000. During this 5 to 6 week combined timeframe the family endured a litany of systemic shocks due almost completely to an absence of forecasting. These shocks—extrinsic to the fact of a loved one's condition—began early in the ICU in 2004 (first parent's hospitalization) and continued throughout intake into hospice in 2005 (second parent's hospitalization).

Some of the extrinsic shocks we experienced imposed immediate hardship in the form of physical exertion by an elderly spouse to rectify administrative medical mistakes (DNR status not charted). Some extrinsic shocks so disturbed the family equilibrium that we postponed treatment plan decisions by several days while we absorbed withheld information and then

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debated and parsed its ramifications.⁸ During these events the patient languished and the cost rose.

During one end of life hospitalization, the absence of forecasting resulted in us being robbed of irreplaceable opportunities to commune with our loved one, and to receive healthcare direction/wishes from our loved one, who we did not recognize as dying. This was due to not recognizing certain behaviors associated with dying, and not being so advised by any medical treatment provider—even though days elapsed during which the family, had it been informed, could have processed the possibility of our loved one’s death.

Although the patient received treatment that was medically sound from a clinical perspective, the patient-family experience was as close to a complete failure as is possible. Patient-families who do not subject themselves to these sorts of experiences are better positioned to experience success.

I cite our personal experiences as illustrative. Unfortunately, such stories play out daily for many families state-wide and nationally.⁹

(5) How will the program(s) included in the proposal be governed and administered?

Regarding PEACE the educational outreach—unknown.

⁸ Our family unit was small (four persons at the beginning of these events); in legal compliance (the entire suite of relevant documents were signed and in effect); congruent (we had conducted what we thought was extensive advance planning and were all “on the same page,” presenting a unified viewpoint to treatment providers); and accessible (part of a social group that embraces and desires the right/need to know about the patient-families’ medical condition as it unfolds).

⁹ A point brought home multiple times during interviews I conducted with “plain folk” and members of every professional medical group I engaged during two years of research.

Regarding physician licensure including significant palliative and end of life training—by statute and current licensing bodies.

(6) To the best of your knowledge, will any federal or state laws or regulations need to be changed to implement this proposal (e.g. federal Medicaid waiver, worker's compensation, auto insurance, ERISA)? If known, what changes will be necessary?

I believe that the federal Medicare Hospice Benefit would have to be amended to allow certain curative treatments with primarily palliative effect to be administered to a patient receiving hospice benefits.

(7) How will your program be implemented? How will your proposal transition from the current system to the proposal program? Over what time period?

The transition would be immediate upon passage of any requisite legislation.

c) Access

(1) Does this proposal expand access? If so, please explain.

PEACE expands access by expanding awareness of available options for hospice care in enough time for patient-families to take full advantage of them. With ample lead time, people can consider the alternatives, family desires, and parse their assessment of dying and death in the knowledge that humane alternatives exist to hospitalized dying`.

If other than covered Medicare Hospice Program services are subsidized, then access will be expanded. Dying at home has the potential (if not likelihood) to require extra-family support

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services that grow as the time of death nears, depending upon the (un)availability of family members.

PEACE expands access to in-hospital palliative and humane end of life treatment for those dying in hospitals by requiring physicians to undergo training adequate to provide it.

(2) How will the program affect safety net providers?

Unknown

d) Coverage

(1) Does your proposal “expand health care coverage?” (Senate Bill 06-208) How?

If other-than-covered Medicare Hospice Program services are subsidized, then coverage would need to be expanded. Dying at home has the potential (if not likelihood) to require support services that grow as the time of death nears, dependent upon the (un)availability of family members.

(2) How will outreach and enrollment be conducted?

Enrollment would not change from existing enrollment: pick up the phone and call hospice after achieving eligibility.

Outreach would consist of a proactive state public awareness campaign utilizing all forms of media and a legislative declaration regarding end of life options, realities, and costs.

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(3) If applicable, how does your proposal define “resident?”

A Colorado resident is any person with a Colorado domicile or staying at a Colorado address.

e) Affordability

(1) If applicable, what will enrollee and/or employer premium-sharing requirements be?

Not applicable. Enrollees will be covered under existing Medicare hospice coverage, additional Colorado hospice coverage if any, and will continue to have to pay out of pocket for any non-covered services.

(2) How will co-payments and other cost-sharing be structured?

Unknown or not applicable

f) Portability

(1) Please describe any provisions for assuring that individuals maintain access to coverage even as life circumstances (e.g. employment, public program eligibility) and health status change.

Not applicable.

g) Benefits

(1) Please describe how and why you believe the benefits under your proposal are adequate, have appropriate limitations and address distinct populations.

The primary benefits are to guarantee that patient-families opting into PEACE will not have to endure loss of dignity and control in the hospital setting; that patient-families will be guaranteed not to suffer the systemic shocks endured during hospitalization due to discontinuity of care and lack of forecasting; that patient-families will not lose irreplaceable last opportunities for communion and receiving care direction from the dying loved one that are intrinsic to a lack of forecasting. An intrinsic benefit is cost savings.

These benefits are adequate to remedy the problem for those who perceive hospitalized dying as problematic. All populations are equally addressed by PEACE's benefits (unless we weigh the advantages to populations who may be predisposed not to avail themselves of current hospice alternatives).

PEACE's primary benefits are appropriately limited in regard to those whose viewpoints preclude assisted-suicide or assisted dying, because extending hospice eligibility is neither.

The secondary benefit is that, after citizens at large become aware of PEACE and its guarantee of a dignified, pain-free, non-institutionalized dying choice, a personal and societal "space" may open up in which we, as individuals and a society, can begin to come to terms with dying as the last phase of living. Over time, by realizing that the four basic fears (loss of dignity/control, pain, dying, death) have been reduced to two (dying, death), more people might be attracted to The Option to Die in PEACE.

(2) Please identify an existing Colorado benefit package that is similar to the one(s) you are proposing (e.g. Small Group Standard Plan, Medicaid, etc) and describe any differences between the existing benefit package and your benefit package.

Unknown

h) Quality

(1) How will quality be defined, measured, and improved?

Quality will be defined and measured by patient-family experiences and their assessment of those experiences. Mission Directors and Pastoral Care department members, palliative initiative executives and leaders will also be in a prime position to monitor patient-family experience. To the extent hospitals are sensitive to statistics on how many people die in their facility, they can benefit from reduced numbers of such occurrences.

(2) How, if at all, will quality of care be improved (e.g. using methods such as applying evidence to medicine, using information technology, improving provider training, aligning provider payment with outcomes, and improving cultural competency including ethnicity, sexual orientation, gender identity, education, and rural areas, etc.?)

Adding a significant palliative and end of life training requirement for physician licensure improves provider training and cultural competency. Educating citizens to other-than-hospitalized dying improves cultural competency. The benefits of PEACE extend equally to all citizens regardless of their sexual orientation, gender identity, education, and domicile. One could say that PEACE stands to improve the experience of non-mainstream citizens by

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precluding their placement in institutions which, by their nature, tend to be less welcoming than individuals' own homes.

i) Efficiency

(1) Does your proposal decrease or contain health care costs? How?

PEACE absolutely decreases healthcare costs, as well as non-healthcare costs associated with hospitalizations (travel, room and board for family members, wear and tear on hospital facilities).

The primary cost reduction is due to hospitalization not happening for X number individuals, for X number of weeks or months, in pre-terminal and active dying phases. All the costs associated with hospitalization will be saved, multiplied by the number of people who die in PEACE.

(2) To what extent does your proposal use incentives for providers, consumers, plans or others to reward behavior that minimizes costs and maximizes access and quality in the health care services? Please explain.

PEACE's consumer incentives are easily understood by citizens once they become fully aware of alternatives to end of life hospitalization. People who want hospitalized dying would remain free to pursue and obtain it under the same conditions that people currently do, pursuant to their insurance coverage and means.

The covered hospice benefit and intrinsic benefits of dying a PEACEful death present a clearly rewarding contrast to a hospitalized dying trajectory.

Once a social conversation has begun, others will emerge to fill the voids in public understanding of the nature of hospitalized dying, how hospitals function, what hospitals actually provide, and how to effectively (as possible) manage hospitalization. Already, the number of books addressing the related topics of end of life, palliative care, and hospitalization are increasing. Most are written by system insiders, with varying degrees of communicative success. Rarely, a lay person like myself offers an out-of-the-box assessment and description of what people encounter, why, and what to do about it.

(3) Does this proposal address transparency of costs and quality? If so, please explain.

Hospital, physician, and surgical costs are not estimated or presented up front; you stay hospitalized and the costs accumulate. One can argue that quality doesn't exist in these settings except if measured by efficacy of each treatment, a benchmark that goes against the grain of palliative care in addressing the whole person and the whole family. I would argue that quality itself is a very opaque notion for hospitalization in general and especially regarding terminal hospitalizations. The best way to begin achieving a quality demise is to avoid hospitalization to begin with, if one is so inclined—which one might be if well informed.

(4) How would your proposal impact administrative costs?

I can only assume PEACE would reduce administrative costs due to patients not entering the hospital system and engaging the many providers that revolve around it.

j) Consumer choice and empowerment

(1) Does your proposal address consumer choice? If so, how?

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PEACE emanates from and personifies consumer choice. Just because we utilize and benefit from medical technology to extend our lives, it does not follow that the government, institutions, and doctors ought to control our dying and deaths. And control they do in the hospital setting. Notions of patient-family autonomy and directives being honored are fuzzy, if not moot, when push comes to shove. One Mission Director of a prominent Denver area hospital acknowledged this is generally the case after I described the following experience:

My father had driven himself to a hospital, ambulated in and had himself admitted to undergo stress testing to determine his eligibility for a cardiac pacemaker. Blood-borne infection took root, and after several days he was debilitated. He had one criteria regarding surgery to drain a wrist infection: no intubation. Due to 70% diminished heart capacity he was ineligible for a local anesthetic or nerve-block approach. General anesthesia was the only viable option. The three person patient-family members (the principal and two adult children / co-medical agents, one a newborn ICU nurse) were congruent in this, the patient's sole treatment specification. The treatment choice was 1) relieve the infection, then see if the debilitated patient's catheterization-induced bladder infection would subside and his innate strength return, allowing his return home; or 2) die.

The anesthesiologists refused to accede to the patient's wishes. The patient was no-code status with an effective Do Not Resuscitate (DNR) Order and at significant risk of a cardio infarction during any surgery—which, had it occurred, would have resulted in an entirely acceptable, if regrettable, demise on the operating table (a scenario with which the anesthesiologists accepted from an ethical perspective). They would not allow the reduced possibility of demise post-op due to a lesser chance of respiratory failure requiring the introduction of life-support technology (intubation).

Although these doctors gave of their time in conversation with me, they failed to offer any alternative at that time. They made no mention of finding other doctors, beyond the immediate

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anesthesiologist team, who might proceed as the family wished. No mention was made of an ethical conundrum requiring that we seek the hospital patient liaison (whom we believed to be ineffectual), or chaplain, ethics committee, case manager, or risk manager (resources that we didn't at that time know existed). Nor did the in-hospital hospice intake process inquire into how we had reached that point clinically and whether or not any alternatives existed. The patient-family choices were foreclosed; death was the only option (and is what occurred four days later). Our father was either too debilitated to go home to his assisted living apartment, where he preferred to be (which at that time would not accept him back, a situation which has since changed), or getting him there would have cost thousands of dollars (a covered expense? an out-of-pocket expense?).

This circumstance exemplifies that although much press is given to patient rights and choice, and despite The Joint Commission's support of rights, and although law mandates choice, in the end systemic notions of appropriate treatment and legal liability overrule patient-family wishes, no matter how well the patient-family presents to the system and regardless of DNR status.

The ultimate patient-family choice is the choice not to enter the system at all for that last, terminal hospitalization. My research indicates that between hospice and enlightened assisted living policies, this choice essentially exists today for people living in their own homes, family homes, or assisted living quarters. As a practical matter, availing ourselves of this choice requires 1) that we know about it, 2) understand hospice for what it is and, importantly, is not (it's not euthanasia), and 3) have this knowledge well in advance of needing it.

The American attitude toward dying and death is a problem shared by the system and by the citizenry. Some doctors have written articles published in major weekly magazines and books about their awakenings, which often occur when either they or their loved ones are hospitalized and subject to the same problematic treatment that everyone may experience. A local hospice director shared how doctors she knows have confided that they would be relieved if their patients

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would ask for hospice. A terrible denial exists, a discomfort with dying and death and a refusal to discuss it. The refusal is perched on a unique precipice for practitioners, who risk being accused of abandonment if the patient-family believes that a doctor has broached the topic prematurely.

The value of independence intrinsic to American culture is one of four key elements governing how end of life plays out in the hospital.¹⁰ True independence would have individuals decide, based on evidence and facts, whether or not to enter the hospital near or at end of life—especially if one has been on a revolving door between hospital and home (as is increasingly typical given the nature of advanced age and the frailty which accompanies it as multiple disease states are managed and life extended¹¹). In order to make such an assessment people need months, if not years of advance time to come to grips with their own dying and death in contemporary American culture.

(2) How, if at all, would your proposal help consumers to be more informed about and better equipped to engage in health care decisions?

Independent choice requires knowledge. If the Commission's and the Legislature's goal is to empower the citizenry, increase choice, improve quality of care, and reduce cost, an educational outreach is one of the most cost-effective programs compared to the cost of technology and layers of administration. Becoming informed about end of life options requires more than just cognitive exposure to alternatives. Becoming informed requires that families digest, soul-search, come to conclusions, and have the time to plan their enactment. Lead time is the primary tool which will help families become better equipped to engage in this most vital of health care decisions.

¹⁰And a Time to Die: How American Hospitals Shape the End of Life, Sharon Kaufman, Scibner, 2005.

¹¹ Kaufman

k) Wellness and prevention

(1) How does your proposal address wellness and prevention?

PEACE addresses wellness and prevention intrinsically. It's all about wellness during the most poignant times. It's all about preventing the loss of what's irreplaceable, and opening up space and possibility for a richer exit from our earthly existence.

l) Sustainability

(1) How is your proposal sustainable over the long-term?

I see PEACE as self-sustaining. It costs little. It offers a lot. At this writing a legislative endorsement of PEACE would serve as a wedge, offering the potential to open up the conversation about humane dying and death in Colorado.

(2) (Optional) How much do you estimate this proposal will cost? How much do you estimate this proposal will save? Please explain.

Cost: unknown. Savings: multiply the average out-of-pocket costs for hospital demise by the number of people who might opt out of that pathway; multiply the average insurance cost by the number of people opting out, minus the cost of at-home / hospice care.

(3) Who will pay for any new costs under your proposal?

PEACE: unknown

Licensure: medical schools would bear the cost of curriculum changes. Licensing authorities would bear the cost of verification that candidates and licensed physicians had completed training as required.

(4) How will distribution of costs for individuals, employees, employers, government, or others be affected by this proposal? Will each experience increased or decreased costs? Please explain.

Unknown

(5) Are there new mandates that put specific requirements on payers in your proposal? Are any existing mandates on payers eliminated under your proposal? Please explain.

Unknown

(6) (Optional) How will your proposal impact cost-shifting? Please explain.

Assuming eligibility for the federal Medicare Hospice Benefit, cost would be shifted to tax dollars collected by the federal government.

(7) Are new public funds required for your proposal?

Unknown

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(8) (Optional) If your proposal requires new public funds, what will be the source of these new funds?

Unknown

How This proposal is Comprehensive

Although the funding requirements and methods for PEACE are unknown to me at this time, I believe PEACE to be a comprehensive proposal according the Commission's guiding principles:

- *PEACE increases coverage and reduces costs* by raising awareness of existing end of life care options, expanding access to them, and potentially reducing the number of Coloradans dying expensive hospitalized deaths.
- *PEACE protects and improves the health status of all Coloradans* by adding a requirement for palliative and end of life training and licensure for physicians, and by championing choice and humane end of life alternatives to institutionalized dying
- *PEACE expands coverage of essential health care services*, with a potentially special beneficial effect on the uninsured and underinsured during particularly vulnerable times.
- *PEACE aligns incentives for high-quality, cost-effective coordinated care* by removing the cost of hospitalized dying during which patient autonomy can be circumvented, replacing that scenario with economical at-home, pain-relieving, personalized, humane end of life care.
- *PEACE supports a system that is financially viable, sustainable, and fair for all* due to its comparatively modest costs and electibility by individuals.
- *PEACE provides opportunities for meaningful choice and encourages personal responsibility*, by informing the public about end of life options well before they're needed so citizens, alone, as families, and en masse, can engage in conversation about dying and death, mapping the realities of hospitalization against those of home-based dying.

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- *PEACE* emphasizes wellness, prevention, health education, and consumer empowerment; in fact PEACE is all about these attributes.

How this Proposal Was Developed

I am a lay person who has experienced the unexpectedly shocking demise of both parents. The egregious shocks our patient-family experienced were beyond the intrinsic shock of a loved one suddenly down and dying. The real shocks were administered by several hospitals and their treatment team members, separated by several years' time, based on procedures that represent the antithesis of care. I do not blame them; I do hold them accountable (a responsibility that I, as a "consumer," share).

My family thought we learned the ropes during Mom's demise. We were intelligent. We had planned in advance We had executed suites of legal documentation. We were congruent. We presented well to the system. We attempted to engage the system to provide care in the true sense of the term—care which the system, through its established communications, leads us to believe it provides.

We were wrong.

We discovered this again and again. The most memorable lessons occurred during three ethical conundrums associated with different resuscitation scenarios. Each situation could have been forecast to us yet was not, resulting in severe extrinsic shock at those times. Each shocking event greatly interfered with the course of treatment by needlessly delaying choices and prolonging patient languishing. The ethical problems exposed the nature of the course of treatment and of dying in hospitals (I analyze these in my forthcoming book in a thirty page chapter titled *The Complete Do Not Resuscitate Conversation*).

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After my father's death, I ruminated on our experiences and began formulating theses about why hospitalization is experienced by patient-families as careless, cold, and problematic. I investigated the nature of hospital communication (what is and what is not communicated); differences among hospitals (urban/rural, profit/not-for-profit, etc.); the underlying principles governing our treatment; and the nature of dying today. I corroborated my theses through interviews with lay people like myself, and through discussions over the course of two years with professionals including nurses, doctors, bioethicists, ethics committee members, patient liaisons, hospice executives, chaplains and mission/pastoral care personnel. I read what appears to be the cream of the crop in current writing about these matters (where "current" means within the past fifteen or so years).

When I mapped my experience against information contained in books by the ultimate insiders—the doctors themselves—I found, surprisingly, that they failed to cover the most vital aspects of our experiences...*why* we expected certain things and got their opposite; *what* we must do to ensure care—distinct from bodily repair services—for our hospitalized loved ones (and ourselves); *how* to parse the ethical gray zones that comprise the framework around, safeguards about, and the application of resuscitation—and most importantly, how that plays against family wishes during the course of treatment, whether non-terminal or terminal.

My family experiences are illustrative. Unfortunately, such stories play out daily for many families state-wide and nationally—a point underscored by almost every professional and lay person I interviewed during a two year period.

My investigation's first result is my forthcoming book that will help citizens manage both hospitalizations and consider the conditions of their or their loved ones' demise, *Dying To Know (And Why You Shouldn't Wait That Long: Effectively Manage Your Loved One's Hospitalization)*. At the start my vision did not include end of life reform. Now, I see end of life

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reform as one of the major tasks of the Boomer generation. End of life reform is critical for millions our parents who are about to die, for we who are next, and for the sake of our children, who ought not have to endure what my patient-family endured not once, but twice. End of life reform has the potential to reduce and contain costs for families and for society.

The second result is this proposal. Thank you for considering these matters of truly *vital* importance to all Coloradans.

Key Reading

1. ...And a Time to Die: How American Hospitals Shape the End of Life, Sharon Kaufman, Scibner, 2005
2. Last Rights: Rescuing the End of Life from the Medical System, Stephen Kiernan, St. Martin's Press, 2006
3. 3 Secrets Hospitals Don't Want You To Know: How to Empower Patients, Mark Meaney, NIPR Press, 2006
4. Mending Bodies, Saving Souls: A History of Hospitals, Guenter Risse, Oxford University Press, 1999
5. How We Die, Sherwin Nuland, Vintage, 1995
6. Dying Well, Ira Byock, Riverhead Books, 1997
7. 24/7 or Dead, Jari Holland Buck, Author House, 2006
8. You: The Smart Patient, Michael Roizen, Mehmet Oz, and The Joint Commission, Free Press, 2006
9. How to Get Out of the Hospital Alive, Sheldon Blau and Elaine Shimberg, Macmillon, 1997
10. Help Me to Heal, Bernie Siegel and Yosaif August, Hay House, 2003
11. Terri: The Truth, Michael Schiavo, Dutton, 2006
12. Dying To Know (And Why You Shouldn't Wait That Long): Effectively Manage Your Loved One's Hospitalization, Axiom Action, 2007 (forthcoming)

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