The Promised Landing

A Gateway to Peaceful Dying

Medical Aid in Dying Excerpt

Bart Windrum

author of Notes from the Waiting Room

The Promised Landing

A Gateway to Peaceful Dying

This pdf excerpt contains an appendix section addressing Medical Aid in Dying from both the civilian and medical professional experience.

I've "wrapped" the excerpt with some of the book's front matter, the index, and rear covers so that those unfamiliar with me or the book may get a sense of this work.

Bart Windrum

2018

Other books by Bart Windrum

Notes from the Waiting Room:
Managing a Loved One's End-of-Life Hospitalization

How to Efficiently Settle the Family Estate

Bart Windrum is available for speaking engagements and workshops
Bart@AxiomAction.com
Obtain other contact information at AxiomAction.com

The Promised Landing: A Gateway to Peaceful Dying

Publisher's Cataloging-In-Publication Data
The promised landing: a gateway to peaceful dying/Bart Windrum.
viii, 216, 23cm
ISBN 978-0-9801090-4-7
ISBN 978-0-9801090-5-4 eBook
1. Death—Terminology 2. Death—Psychological aspects 3. Death—Planning
I. Title II. Author PE1599.D4
Library of Congress Control Number: 2017916996

Book Design, Cover Design, Graphics: Bart Windrum
Typefaces: Trajan Pro, Stone Serif, Stone Sans
Technical production consulting: Jay Nelson
Author photographs: rap, Dave McCollum; portrait, Will Eiserman
53 color Matrix graphic images

1 3.18

For those who have the sense
that the implied promise of conventional end-of-life guidance
leaves too much unaddressed,
and who want to keep their own end-of-life promise
to die in peace, and at peace.

Contents

Why

Our Dying Territory: Identifying and Naming our Dying Situations

Obstacles to Peaceful Dying and How to Mitigate Them

And So

Lexicon

My mother's unexpected hospitalized demise during January 2004 and my father's error-caused demise during the spring of 2005 were unnecessarily painful events for our family. In response, I became activated and developed an end-of-life body of work to help each of us achieve the peaceful deaths to which we aspire. This lexicon—a set of insights and assessments describing a worldview—identifies personal and systematized obstacles to peaceful dying and how we may mitigate them.

From 2005 through 2008 I authored *Notes from the Waiting Room: Managing a Loved One's End-of-Life Hospitalization* and *How to Effectively Settle the Family Estate*. During 2012–2013, I presented a TEDx talk, "To Die in Peace: New Terms of Engagement"; wrote, arranged, and performed the "Never Say Die Rap"; published the article, "It's Time to Account for Medical Error in 'Top Ten Causes of Death' Charts" in the *Journal of Participatory Medicine*; and created a unique end-of-life visioning tool, "Windrum's Matrix of Dying Terms."

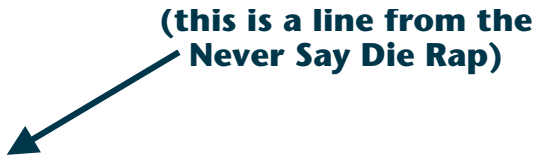
Windrum's Matrix is this book's primary focus. The Matrix names the array of dying situations ahead of us. It frames them as our *dying territory* containing destinations that we can learn to aim toward and, as importantly, aim to avoid.

In 2014 I completed the lexicon, formalizing it as a program and naming it "To Die in Peace: Our Rights of Passage." Windrum's Matrix is the entrance to the program.

The Promised Landing serves as a gateway and as a guide to the entire lexicon.

Chart your glide path while there's time
to die in peace with minimal cryin'
Study up, make some sense
of 21st century impediments
Time to grow up before we get old
There's more to dying than we've been told
Wishing won't help us turn the page
So 17 new terms to engage
I have a Matrix for that…

— from the *Never Say Die Rap*



No Bro Ma'am You Ain't Goin' Nowhere:
On the Availability of Medical Aid in Dying

I support medical aid in dying despite its challenges and the shortcomings associated with its implementation. Yet it should be abundantly clear that To Die in Peace: Our Rights of Passage is not about aided dying. Obstacles to peaceful dying will persist no matter where aided dying becomes legal. Remember: dying in peace pertains to the months, weeks, and days of our demise, during which we likely will seek and need to manage medical treatments so as to obtain their benefits yet keep from getting dragged into dying situations we know we wish to avoid. Medical aid in dying (MAID), also known as physician-aided dying, is about choosing and controlling, insofar as possible, the moment we die—personally directing our dying to maximize our chance of dying in peace.

In our dying territory, represented by Windrum's Matrix of Dying Terms, MAID is successfully utilized when the patient-family experiences either Released or Postponed dying. Those who wait too long and can no longer meet the laws' requirements experience Failed dying—essentially a placeholder for Endstate, Suspended, Repetitive, or possibly Vegetative dying. For those who value and aim for aided dying, its availability matters, a lot.

I have long seen the emergence of aided dying as a logical civilian response to generations of overly hard dying afflicting millions of dying people and multiple millions more of their surviving loved ones. Think about these numbers—peace-less dying has become an epidemic. Civilians cannot change medicine; medical professionals can barely make a dent in medical culture and practice even when they're inclined to. Enacting medical aid in dying is one small change that citizens are successfully making in the end-of-life realm.

In Colorado, USA, where I live, I helped pass the Colorado End-of-Life Options Act by gathering signatures to place it on the ballot and by writing articles and editorials arguing for its passage. The law took effect late in 2016. As previously noted, six months after its passage, I was asked to serve as a witness on an elderly friend's request form used to initiate the process, and thus unexpectedly took a ringside seat to their family's travails in attempting to locate participating doctors at more-or-less the last minute. The same struggle to find willing doctors recurred three months later for a friend helping a friend navigate this new territory. So I have a fresh set of insights regarding challenges associated with implementing and accessing such a paradigm-shifting law.

Let's examine important aspects for those wanting to access medical-aid-in-dying services under newly-established laws. Since these laws involve both civilians and medical professionals, let's look at aspects that pertain to each group. What follows is informed by my exposure in general and by the statute where I live; details and aspects may differ in different jurisdictions.

Civilian Problems Accessing Medical Aid in Dying

The civilian sector appears to have several misapprehensions about aided dying. The first has to do with access to it. Essentially, people seem to think that gaining access to aided dying will be

quick, as casual as purchasing some personal item. And that death after ingestion will be very fast (it may, or it may not…). And that some system for providing the service and products it requires will have been established when the law takes effect. And that medical systems and doctors support or even know about it.

If ever a law needed reading, your jurisdiction's aided-dying law is it. Google it, download it. If your computer skills allow, convert the hard-to-read all-capitalized legal document to sentence-caps (normal everyday capitalization). The Colorado End-of-Life Options Act runs 11 pages. It's an easy read. This webpage links to the legislative texts of existing laws: TheIrisProject.net/resources-on-physician-assisted-death.html

Aided dying is not a turnkey system. It is not immediately, universally, easily, or readily available. It's hard to access because we must find and become patients of doctors who are willing to engage. Doctors' engagement is *not* mandatory. Those who do so may not publicize their availability or want it publicized. This also applies to health systems with which doctors associate.

In general, to qualify one must be a resident of the jurisdiction. While no end-of-life medical "tourism" is allowed, gaining residency can be quick. If you live outside of the jurisdiction you'll need to research how to become a resident (don't expect MAID laws to detail how) and prove it when requesting MAID. One must be dying and diagnosed as such. Currently in all U.S. jurisdictions, you must be diagnosed by two physicians as terminal, with six months or less left to live. You must be mentally competent from start to finish (advanced dementia sufferers likely need not apply).

Practically speaking, one must be physically able to travel to and from the necessary appointments. One must be able to afford the cost of the prescribed drugs—do not be surprised if their cost magically multiplies in jurisdictions where MAID is being contemplated or has become law. One must be able to ingest the lethal prescription by oneself (others may help to prepare it). One should

have at-home assistance (do not expect that hospitals will allow MAID to take place in their facilities). One may need to keep secrets to prevent unwanted interference from residents and management of corporate-owned shared living facilities, even if those entities have not banned MAID on their premises. Expect most hospices to decline participation or to take a very limited role in your personally-controlled death.

Finding willing health systems and doctors will probably take a lot of time, especially right after a law takes effect and possibly as an ongoing condition. Six to eight weeks may be typical, four if you're lucky, unless you're already a patient of a doctor who has publicized their availability. One may be a patient of, say, a willing surgeon but encounter resistance if the large health system's specialty clinic that the doctor is associated with doesn't consider you a patient of the clinic also.

Another potential delay relates to the drugs prescribed. Under Colorado's law, businesses and individuals may opt out in various ways. Individuals can morally and ethically object. Pharmacies may decline to stock the required substances. For certain formulations, a process known as compounding may be required; few pharmacies are "compounding pharmacies." A hidden snafu might also be a pharmacy's wholesale distributor that supplies a given retail location—if the distributor doesn't carry the drugs, the pharmacy cannot obtain them.

So the essential problem is that people mistakenly believe that MAID is casually available and accessible, anytime, anywhere. People wait too long to decide to seek MAID and risk failing to obtain it. In the case I was privy to, a 90-year-old dying person and their proxy had to endure, while seriously failing, multiple round trips across a large metropolitan area to meet with the doctors, apply, qualify, and obtain the prescriptions. They very nearly didn't make it—they very nearly landed in Failed dying.

Lastly, a medically-aided death is, in fact, a medical treatment

requiring the full range of advocacy skills by proxies and family members: forecasting, knowledge, and supervision with as much diligence as for any other medical treatment.

Medical Professionals' Challenges in Providing Aided Dying

The other misapprehension that civilians are under is what it takes for medical professionals to engage in MAID. Engagement may be split into two aspects: administrative and technical.

Administratively, most doctors work with or for health systems, facilities, or large group practices which may, at the corporate level, decline to participate. Populations in rural areas served by a single system that opts out will need to go elsewhere to find willing doctors. For systems opting in, policies and procedures must be developed to govern how the system will manage, coordinate, and deliver aided dying. Since MAID is a profound paradigm shift, the people comprising the system may go through individual and collective soul-searching before opting in or out and before designing their policies and procedures. If you or your loved one are among the first applicants, expect to encounter confusion and uncertainty.

Doctors are not trained to purposely end life. This is apparent especially in the United States where, unlike British Columbia, Canada, euthanasia by injection is illegal; dying people must independently ingest the lethal agents (currently the only delivery method is oral; I am interested in but do not expect to see an intravenous method introduced in the United States). The laws do not require that physicians undergo any particular training. So doctors are on their own to assess each patient and, in consultation with colleagues and pharmacists as they see fit, to devise a reliable lethal "cocktail" on a case-by-case basis.

In the gentlest cases, death will be very quick—five to 15 minutes. Or, death could take five to 15 hours or even some days. We don't hear about longer deaths during legislative or election campaigns.

In the case I was privy to, the dying person's death took 11 hours. It was completely peaceful for the dying person but nerve-wracking for the attending adult child proxy. The hospice that they enrolled in was slow to assist and of limited help. Essentially, the two-person family was on its own.

Apparently, there's much for doctors to consider. Patients with many comorbidities may have an easier time dying than patients who are dying from one severe condition but whose bodies are otherwise strong. As a layperson, I'd express this by saying that a complete medical history needs to be known and understood at a deep level to maximize the chance for quick dying. There is no one-size-fits-all lethal agent.

For all these reasons, accessing aided dying is tough, most especially in the first year after each law takes effect. Perhaps surprisingly, these troubles persist even in jurisdictions like Oregon, now in its 21st year offering aided dying. Compared to another paradigm shift, it's ridiculously hard. In states where cannabis is now legal, adult residents can walk into any retail vendor and upon showing ID, immediately buy cannabis in many forms, walk out and drive home with their purchase. It is actually harder to find and obtain aided-dying services today than it was buying illegal cannabis from the 1970s to the 2010s. It seems to me that on a social scale both of these reforms represent deep change, are equally complex, and are managed very differently.

Lastly, my own reflection as one who worked to pass a law where I live and who has subsequently, if only tangentially, helped a dying person use it: dying and death is profound for all involved, a lesson that death literacy abundantly teaches. Dying in peace requires that we become hands-on involved. To do well, we must approach dying matters with humility and compassion as well as resolve.

— —

For people whose condition or timing make them ineligible for aided dying, Voluntarily Stopping Eating and Drinking (VSED) may be a viable pathway. Consult these books to learn more:

- *The Best Way to Say Goodbye*, Stanley Terman, MD, 2007, Life Transitions Publications
- *Choosing To Die*, Phyllis Shacter, 2017, PhyllisShacter.com

For people interested in personally directing their dying independent of the medico-legal system and societal norms, read the classic *Final Exit* by Derek Humphry.

Index

O

P

Q

R

S

THE PROMISED LANDING: A GATEWAY TO PEACEFUL DYING provides a new context for understanding our dying experiences as shaped by western culture. Learn to identify and distinguish between the various dying situations that frame our journey toward, or away from, the peaceful demise we want for ourselves and our loved ones. Participate in a personal (or group) guided recitation, traveling to every way station and destination throughout our dying territory—engaging your heart and soul, where resolve for fulfilling our promises takes root. Then, examine a related set of everyday personal and systemic obstacles to peaceful dying in order to better forecast their impact and adjust glide paths while time yet remains to die in peace, and at peace.

Bart Windrum is one of the most brilliant and original thinkers I know in the citizen movement to improve our experience of death and dying. If you want to avoid pitfalls and improve your odds of a peaceful death—on your own terms, not medicine's—read this book.
Katy Butler, author of *Knocking on Heaven's Door*

Bart Windrum's end-of-life lexicon draws out a wide range of ethical, medical, cultural, practical, and family issues. His introduction of language shifts is an important contribution to this complicated dialog and a gift to all of us.
Dennis McCullough, MD, author of *My Mother, Your Mother: Embracing Slow Medicine*

Contemplative aging requires that we learn to identify, recognize, and mitigate practical obstacles to peaceful dying that our world, too readily and frequently, sets before us. Bart Windrum deeply illuminates these matters.
Rabbi Zalman Schachter-Shalomi, former Naropa University Wisdom Chair and author of *From Age-ing to Sage-ing: A Revolutionary Approach to Growing Older*

The Promised Landing lays out a map of our dying territory as a matrix, charts its intersecting paths, and discusses obstructions in the way of a peaceful death. Bart Windrum is a warm writer and has written a smart book which will be useful to all of us who see little of dying and death, until we see too much.
Victoria Sweet, MD, author of *Slow Medicine* and *Gods' Hotel*

Windrum's Matrix of Dying Terms significantly enhances end-of-life discourse. If widely adopted, the Matrix would advance our ability to talk about these realities, offering insight to policy makers, clinical providers, and citizens in our collective management of dying in America.
Jennifer Moore Ballentine, MA, Executive Director, California State University Institute for Palliative Care

Thank you for an incredibly rich trove of advice. Your work is a light in the darkness.
Susannah Fox, US authority on technology and health care

ISBN 978-0-9801090-4-7
90000
9 780980 109047