

My Story, My Way: Designing the Final Chapter

PREFACE

When my father died I asked the doctor what was the cause of death. He said it was from ODTAA. Not being familiar with that, I asked if it was some type of weird condition or disease. No the doctor said, it means “One Damn Thing After Another.” That is why I think our bodies are like automobiles; when the thing starts breaking down and its one damn thing after another, we get rid of it. With cars we can trade it in for a new one but we don’t have that luxury with our bodies. But to a large extent the thought process is the same.

With both, hope springs eternal. We hope that the old jalopy can make one more trip but at some point the fear of breaking down on the highway overtakes our hope and we know it is time to trade in the clunker. Even though hope is not a plan, for too many hope is THE plan – and then fear happens – and then a decision has to be made. It is at that point, when your fears outweigh your hopes, that you become motivated to develop a plan of action based on something other than hope. Fear or hope, what matters most to you?

To answer that question you must know your fears and your hopes. When it comes to death and dying, what are your biggest fears and concerns? (Physical or emotional pain, dying alone??) What would push you to stay alive? (Attending your daughter’s wedding, seeing a grandchild graduate, watch the Cubs win a World Series??) What trade-offs are you willing to make to achieve your goals.

The purpose of this exercise is to assist you in articulating an answer to these questions, to enable you to find an answer within yourself and to encourage you to discuss your answers with the person who will eventually be called upon to make medical decisions for you.

This by the way is not a final exam. It is the start of a process and one that will continue until the ole clunker can clunk no more.

THE HORIZON

The first step in the process is to walk to your front porch (or wherever you can go that gives you a clear and unobstructed view) and see how far you can see into the horizon. Is it six months, a year, several years? Context makes a difference even in a commingled world of time and space. Circumstances change, stuff happens, and your priorities will look different if you are flat on your back rather than standing. Be aware of that context and remember that this is always a work in progress.

A FATE WORSE THAN DEATH

When is life not worth living? For one patient he wanted his doctor to do whatever was necessary to keep him alive as long as he could watch TV and eat chocolate ice cream. Another patient hated to be in pain; he was prepared to undergo any treatment so long as he could live without pain. Even though these appear to be very broad statements, they are helpful for family members when assessing what

steps to take in caring for your health and, in particular, whether to continue to probe, stick, cut, or whatever to you.

Below are some questions to help you formulate an idea of what condition might be so intolerable that you no longer want to live. These are not absolutes that can be answered with a yes or no but they are guidance for your family. If treatment would not reverse or improve your condition, would you want that treatment if you could.....

1. No longer recognize your family? Probably yes/Probably not.
2. No longer interact/communicate with your family? Probably yes/Probably not.
3. No longer move about and were confined to a bed? Probably yes/Probably not.
4. No longer _____.
5. Are in severe pain most of the time? Probably yes/Probably not.
6. Even if you are find yourself in one of these conditions, would you want treatment in order to stay alive if there was a reasonable chance that you could reach/see/realize another milestone?
 - Probably yes/Probably not.
 - If yes, what is that milestone? _____

None of this is to imply that you need answer any of these conditions as a "probably not." You may be willing to endure anything if it keeps you alive. You will not be the first patient to tell a doctor, "Surely, there is something you can do!"

WHAT ARE THE ODDS

Whether to endure a particular treatment will depend on many circumstances, one of which is the odds of success for any particular procedure. Or put another way, what is the cost of the medical treatment: how much would you be willing to endure if the chances of regaining a reasonable quality of life? What if the chances were high? What if the chances are low?

Imagine that you are seriously ill. The doctors are recommending treatment for your illness but the treatments have side effects such as severe pain, nausea, vomiting, or weakness that could last for months. Would you be willing to endure such severe side effects if the chance that you could regain a reasonable quality of life was:

High (over 80%)	Yes	Not Sure	No
Moderate (over 50%)	Yes	Not Sure	No
Low (about 20%)	Yes	Not Sure	No
Very low (less than 2%)	Yes	Not Sure	No

Time matters. When assessing the pros and cons of medical treatment, even if there is a high probability that you could regain a reasonable quality of life, how long would that last: six months, a year, or more? Would you be willing to endure severe side effects if the chance that you could regain a reasonable quality of life would last:

Less than six months	Yes	Not Sure	No
Between six months and a year	Yes	Not Sure	No
More than a year	Yes	Not Sure	No

WHEN LESS MEANS MORE

It was the poet Ogden Nash who drew the distinction between sins of commission and sins of omission and that:

“...the suitable things you didn't do give you a lot more trouble than the unsuitable things you did.
The moral is that it is probably better not to sin at all, but if some kind of sin you must be pursuing,
Well, remember to do it by doing rather than by not doing.”

Doctors, and the lawyers who sue them, have taken this to heart. Doctors are trained to do things, to take steps to save lives, sometimes without regard to the collateral costs; in the medical/legal system of today, doctors can never be faulted for doing too much. Some studies indicate that patients who saw a palliative care specialist stopped chemotherapy sooner, entered hospice far earlier, experienced less suffering at the end of their lives – and they lived longer. For half the patients in the study, continued intensive care did more harm than good. For the other half, they lived longer when they stopped trying to live longer.

Unfortunately there is no true/false, yes/no, what are the odds type question that tells you when “not doing” is preferable to “doing.” There is no aha moment, no epiphany. Arriving at an acceptance of one’s mortality and a clear understanding of the limits and the possibilities of medicine is a process that cannot be addressed in one conversation but should be addressed in a series of “breakthrough discussions” with your doctors to decide when to switch from time for fighting the disease to time for other things like being with family, traveling, or eating chocolate ice cream.

The point is that people who have substantive discussions with their doctor about their end-of-life preferences were far more likely to die at peace and in control of their situation and to spare their family anguish. In the discussions with your doctor you should address the following issues:

- What is your prognosis? Not only should you have a full and frank conversation about this with your doctor but you should also explain to your doctor your understanding of the prognosis.
- What are your concerns about what lies ahead, both for you personally and for your family? (Many patients are willing to undergo therapies they don’t want if that is what the rest of the family wants.)

- What kind of trade-offs are you willing to make?
- How do you want to spend your time if your health worsens?
- Who do you want to make decisions for you if you can't – or if you are too exhausted to make them on your own?

Not having this conversation is one of those sins of omission that Ogden Nash referred to.

“...don't bother your head about the sins of commission because however sinful, they must at least be fun or else you wouldn't be committing them.

It is the sin of omission, the second kind of sin,
That lays eggs under your skin.

The way you really get painfully bitten
Is by the insurance you haven't taken out and the checks you haven't added up
the stubs of and the appointments you haven't kept and the bills you
haven't paid and the letters you haven't written.”

He aptly pointed out that you never get any fun out of the things you didn't do but you do pay a price for not having done them. Talk to your doctor.

MORE THAN MEDICINE

Errors of commission or errors of omission are not the sole province of the medical providers. In the previous section you weighed the odds of opting for a particular medical procedure; you had to decide whether in saying yes to the treatment you were making a mistake of unnecessarily prolonging your suffering or whether in saying no to the treatment you were shortening what would otherwise be a valued life. Your ultimate decision may depend more on whether you are ready to die than the medical considerations. Is the fear of dying causing you unrelenting depression? Are you afraid that you have become a burden to your family and that they would be “Better off without me.” There are no questions to prepare you for all that may come but when it starts looking like one damn thing after another, you may want to prepare a to-do list to die for.

Have you shared all the memories you want to share either orally or in writing? Have you passed all your words of wisdom? Are there any relationships that need to be resolved: forgive, ask for forgiveness, or just get the last word in? Have you established a legacy or ensured that those left behind will be okay without you? Have you made peace with your God? Are you prepared to meet the end of life on your terms?

The purpose of this exercise is to have those things in place that could cause consternation, confusion or chaos as the end nears. One thing that could create a problem is dissention within the family with the decisions that you or your surrogate have made. Some people appoint an individual, usually a spouse or one child, to make a decision; others appoint all their children and say any one of them can make a decision. Either way there is the possibility of discord.

Is it more important to you:

- a) To have your specific treatment preferences followed even if family members disagree: or
- b) To have family members reach a consensus with whatever decision is made?

When you get to that point of nearing the end of life on your own terms, when you have decided that the race has been run, the war has been waged, and that you are done, then there is yet another legal/medical issue to address.

LIFE SUSTAINING TREATMENT

When you can see the light at the end of the tunnel and you believe that the light is the radiance of the pearly gates, you may want to consider an order to emergency personnel not to use “life sustaining treatment. This is especially an issue for the very frail whose ribs would crack if the EMT attempted to resuscitate such a person. In Maryland this order is called a MOLST, Medical Orders For Life Sustaining Treatment. In Delaware, such an order is referred to as DMOST, Delaware Medical Orders for Scope of Treatment. (The term MOLST is used in this Guide but the principles discussed equally apply to DMOST.)

The MOLST is not to be confused with a Living Will or Advanced Directive. The Advanced Directive is generally prepared by a lawyer and is considered as a legal document whereas the MOLST is a medical order prepared in conjunction with, and signed by, a medical provider. Anyone over age 18 can have an Advanced Directive but the MOLST is designed for those with a year or so of life left.

The essence of the MOLST is to direct emergency technicians not to resuscitate or to provide other life sustaining treatment. Once signed, it is a document that should be left with the patient at all times and is most often taped in a conspicuous location such as the refrigerator door.

The benefit of the MOLST is that it is created when one is fairly certain of their medical condition. This is frequently not true with the Living Will or Advanced Directive that is a boilerplate form signed at the lawyer’s office without any consideration to the medical circumstances that might arise at the time it is used. Because some medical providers are aggressive in protecting what they deem to be a patient’s right to choose, these medical providers will interpret the Advanced Directive as they see fit even if that interpretation is contrary to the wishes of the patient’s family. If you do not want a doctor, hospital or other medical provider interpreting an Advanced Directive that you completed by checking a box willy-nilly at the lawyer’s office, then do not sign the Living Will or Advanced Directive.

WHO DECIDES

Everyone over the age of 18 should have a Healthcare Power of Attorney, that is, a legal document that appoints the person or persons who can make medical decisions for you if you cannot make those decisions for yourself – or even if you simply do not want to make those decisions for yourself. Your Healthcare Power should include a statement like this:

When my life is on a decidedly downward trajectory, I will probably suffer with the physical and emotional distress that accompany many mortal illnesses and will probably compound the pained uncertainty of treatment with the further agony of indecision. In that situation, my Healthcare Representative is charged with the responsibility of making medical decisions for me not only when I cannot make them for myself but also when I don’t want to make them for myself.

However bear in mind that most medical decisions are not unilateral ones but rather are a result of the conversations that you should be having with your doctor. That said, also bear in mind that you are in charge of your treatment. A conversation with your doctor is a two sided

conversation and, like all such discussions, requires a committed speaker and a committed listener. Not all medical providers listen.

If there is a red pill and a blue pill, the paternalistic doctor will tell you, "Take the red pill, it will be good for you." Other doctors will give you the facts and figures and let you decide: "Here's what the red pill does, here's what the blue pill does; which one do you want?" What you are looking for is the doctor who will assist you in interpreting the situation, who will discuss the pros and cons of each pill, and who will present options based on your priorities. It is shared decision making among you, your doctor and your family.

PULLING IT ALL TOGETHER

When serious sickness or injury strikes and your body or mind breaks down, will you be prepared? After the stroke, after the heart attack or after learning that death is sooner rather than later is not the time to start answering all the questions laid out in this guide or to start discussing your answers with other members of the family. Best to do this when you and your family are at ease. Disagreement and discord among family members can have a negative impact on your health and can certainly create anguish when what you need is repose. When they are at peace, you are at peace; if you are at peace, they will be at peace.

Share this guide, and your answers to the various questions, with them. Better yet, review the questions with them as you prepare your answers. You might also want to write out your thoughts in a narrative such as the one attached as an example.

At the end of the day, this is your life and you can seize the opportunity to design the final chapter of that life. Hopefully this guide will be of assistance in that design so that you too can agree with the advice that echoed from the grave of a recently deceased client:

"Life should NOT be a journey to the grave with the intention of arriving safely in an attractive and well preserved body, but rather to skid in sideways, chocolate in one hand, latte in the other, body thoroughly used up, totally worn out and screaming "WOO HOO, WHAT A RIDE!"

May you ride into the sunset in peace!

This guide was based on the following three sources. For ease of composition, in many instances direct quotes were re-printed without quotation marks. If you find this paper helpful, credit is due to the authors of these sources:

Being Mortal: Medicine and What Matters in the End by Atul Gawande (Henry Holt & Company 2014)

American Bar Association Commission on Law and Aging

How We Die: Reflections on Life's Final Chapter by Sherwin Nuland (Knopf 1993)

Also see the April 29, 2017 issue of *The Economist*: How Life Ends – Death is Inevitable. A bad death is not. (One page from the magazine is attached.)

Me and My Life

On the attached pages (My Story, My Way: Designing the Final Chapter) are some questions and answers that give those that I love some insights into how I wish to be treated and cared for when my life is on a decidedly downward trajectory; my answers also explain how I would structure the final chapter of my life to the extent that I have the power to do so. My responses are important to my family because they (or one of them) have been appointed as my Healthcare Representative charged with the responsibility of making medical decisions for me not only if I cannot make them for myself but also when I don't want to make them for myself. I prefer that they be guided by the statements I make here in the calm of the day than whatever utterances I might make in the storm of the night.

Like most people I will probably suffer with the physical and emotional distress that accompany many mortal illnesses, and like most people I will probably compound the pained uncertainty of my last months by the further agony of indecision – to continue to give in, to be treated aggressively or to be comforted, to struggle for the possibility of more time or to call it a day and a life – these are the two sides of the mirror into which we look when afflicted by those illnesses that have the power to kill.

The side in which I choose to see myself reflected during the last days is an image that is tranquil in its decision; dying at home is preferable to dying in a hospital. As a broad statement, unless the probability is appreciably greater than 50% that any procedure would result in at least 6 more months of life, then the pain would not be worth the gain.

What is most important to me is being able to communicate with those I love. For me, my life would hold little or no value if I cannot engage in meaningful communications.

Few people faced with a diagnosis of potentially remediable malignant disease should be willing to give up the struggle if there is any reasonable chance that some promising form of treatment is available to lessen the ravages of the disease or cure it. But what is *reasonable* and what is *promising*? Unfortunately decisions about continuation of treatment are influenced by the enthusiasm of the doctors who propose them.

When I have a major illness requiring highly specialized treatment, I will seek out a doctor skilled in its provision. But I will not expect the doctor to understand my values, my expectations for myself and those I love, my spiritual nature, or my philosophy of life. That is not what he or she is trained for. For these reasons, I will not allow a specialist to decide when to let go. I will choose my own way, or at least make the elements of my own way so clear that the choice, should I be unable, can be made by those who know me best.

The real event taking place at the end of my life is my death, not the attempts to prevent it. However this is not to say that upon the first diagnosis of a terminal disease I will pack it in. Hope is a virtue. But hope lies not in an expectation of cure or even remission of present distress. I will seek hope in the knowledge that insofar as possible I will not be

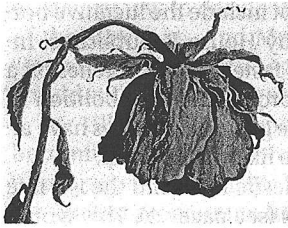
allowed to suffer or be subjected to needless attempts to maintain life; I will seek hope in the certainty that I will not be abandoned to die alone. I am seeking hope now in the way that I try to live my life so that those who value who I am will have profited by my time on earth and be left with comforting recollections of what we have meant to one another. Having the time at the end of my life to recall those moments, to share them, to laugh about them, is much more important than sacrificing those moments for the uncertainty of a few more days, weeks or even months of miserable existence. The price is too high, the risk too great. That above all else is what should guide by care givers.

The totality of circumstances in which we find ourselves can never be known. It is for that reason that I make no "advance directives" to my health care providers. It is for the persons that I have appointed in my Healthcare Power of Attorney to decide after taking into consideration the medical information and my wishes as I have expressed herein and in the attached pages.

John F. Robbert
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How to have a better death

Death is inevitable. A bad death is not



IN 1662 a London haberdasher with an eye for numbers published the first quantitative account of death. John Graunt tallied causes such as “the King’s Evil”, a tubercular disease believed to be cured by the monarch’s touch. Others seem uncanny, even poetic. In 1632, 15 Londoners “made away themselves”, 11 died of “grief” and a pair fell to “lethargy”.

Graunt’s book is a glimpse of the suddenness and terror of death before modern medicine. It came early, too: until the 20th century the average human lived about as long as a chimpanzee. Today science and economic growth mean that no land mammal lives longer. Yet an unintended consequence has been to turn dying into a medical experience.

How, when and where death happens has changed over the past century. As late as 1990 half of deaths worldwide were caused by chronic diseases; in 2015 the share was two-thirds. Most deaths in rich countries follow years of uneven deterioration. Roughly two-thirds happen in a hospital or nursing home. They often come after a crescendo of desperate treatment. Nearly a third of Americans who die after 65 will have spent time in an intensive-care unit in their final three months of life. Almost a fifth undergo surgery in their last month.

Such zealous intervention can be agonising for all concerned (see pages 45-48). Cancer patients who die in hospital typically experience more pain, stress and depression than similar patients who die in a hospice or at home. Their families are more likely to argue with doctors and each other, to suffer from post-traumatic stress disorder and to feel prolonged grief.

What matters

Most important, these medicalised deaths do not seem to be what people want. Polls, including one carried out in four large countries by the Kaiser Family Foundation, an American think-tank, and *The Economist*, find that most people in good health hope that, when the time comes, they will die at home. And few, when asked about their hopes for their final days, say that their priority is to live as long as possible. Rather, they want to die free from pain, at peace, and surrounded by loved ones for whom they are not a burden.

Some deaths are unavoidably miserable. Not everyone will be in a condition to toast death’s imminence with champagne, as Anton Chekhov did. What people say they will want while they are well may change as the end nears (one reason why doctors are sceptical about the instructions set out in “living wills”). Dying at home is less appealing if all the medical kit is at the hospital. A treatment that is unbearable in the imagination can seem like the lesser of two evils when the alternative is death. Some patients will want to fight until all hope is lost.

But too often patients receive drastic treatment in spite of their dying wishes—by default, when doctors do “everything possible”, as they have been trained to, without talking through people’s preferences or ensuring that the prognosis is clearly understood. Just a third of American patients with ter-

minal cancer are asked about their goals at the end of life, for example whether they wish to attend a special event, such as a grandchild’s wedding, even if that means leaving hospital and risking an earlier death. In many other countries, the share is even lower. Most oncologists, who see a lot of dying patients, say that they have never been taught how to talk to them.

This newspaper has called for the legalisation of doctor-assisted dying, so that mentally fit, terminally ill patients can be helped to end their lives if that is their wish. But the right to die is just one part of better care at the end of life. The evidence suggests that most people want this option, but that few would, in the end, choose to exercise it. To give people the death they say they want, medicine should take some simple steps.

More palliative care is needed. This neglected branch of medicine deals with the relief of pain and other symptoms, such as breathlessness, as well as counselling for the terminally ill. Until recently it was often dismissed as barely medicine at all: mere tea and sympathy when all hope has gone. Even in Britain, where the hospice movement began, access to palliative care is patchy. Recent studies have shown how wrong-headed that is. Providing it earlier in the course of advanced cancer alongside the usual treatments turns out not only to reduce suffering, but to prolong life, too.

Most doctors enter medicine to help people delay death, not to talk about its inevitability. But talk they must. A good start would be the wider use of the “Serious Illness Conversation Guide” drawn up by Atul Gawande, a surgeon and author. It is a short questionnaire designed to find out what terminally ill patients know about their condition and to understand what their goals are as the end nears. Early research suggests it encourages more, earlier conversations and reduces suffering.

These changes should be part of a broad shift in the way health-care systems deal with serious illness. Much care for the chronically ill needs to move out of hospitals altogether. That would mean some health-care funding being diverted to social support. The financial incentives for doctors and hospitals need to change, too. They are typically paid by insurers and governments to do things to patients, not to try to prevent disease or to make patients comfortable. Medicare, America’s public health scheme for the over-65s, has recently started paying doctors for in-depth conversations with terminally ill patients; other national health-care systems, and insurers, should follow. Cost is not an obstacle, since informed, engaged patients will be less likely to want pointless procedures. Fewer doctors may be sued, as poor communication is a common theme in malpractice claims.

One last thing before I go

Most people feel dread when they contemplate their mortality. As death has been hidden away in hospitals and nursing homes, it has become less familiar and harder to talk about. Politicians are scared to bring up end-of-life care in case they are accused of setting up “death panels”. But honest and open conversations with the dying should be as much a part of modern medicine as prescribing drugs or fixing broken bones. A better death means a better life, right until the end. ■