

THE TYRANT HOPE

The ability to wonder—if I put it like that it probably doesn't sound to you too much like an advanced skill. It probably sounds more like the ability to land on the ground when you fall: more inevitable than skillful. My wife says that the world would be a kinder place if every man had a tractor, and all I can add to that is that the kindness would be guaranteed if every man was full of wonder when riding it.

It is my experience that the capacity for wonder might be something we share with everything that is holy, and something that is easily and early forsaken by people and times where technique and information are boss. *Wonder is part fascination, part ability to believe in things as they are, part willingness to be confused, even devastated at times, by the epic mysteriousness of ordinary things.* The work of dying that each dying man or woman or child must do demands of each of them some ability to be drawn in, overwhelmed, sometimes devastated and always awestruck by the ordinary death that underwrites their lives. The same is true of their caregivers. Wonder is the sum of life's way of being itself, washing up on the shore of what you've known until now, leaving handfuls of treasure scattered among the small boulders of what you were sure of. You gather

me of that treasure for no reason you can figure without telling anyone and strash it under the pillow of your dreams for a time not quite yet upon you. Wonder is a willingness, decked out as a skill, to be on the receiving end of how vast the world always is and of how unlike your ideas of how should be it often is.



Then I was very young I, probably like you, thought about a lot of things at, so far as I knew, no one else seemed to be concerned about. A few of em were of the “Why is the sky blue?” kind, or the “If the earth is rotating how come I don’t get dizzy?” kind. These questions get your young ordering muscle tuned up for its possible future employment in the aged enterprise of trying to be a real, useful human being in the world, you are lucky enough to be born into a place and time and people that make room for wonder in their schemes and plans. The adults around you and I, though, had found little or no employment for their wondering muscle in the graying, flattening, rationalist, and literalist project of fitting a job and fitting into this part of the world, just as it had been for our elders as well, and so on. So these questions of mine didn’t find any mirror, surviving wonder in most of the people I asked. When I asked those kinds of questions as if much depended on the answers, the answers got solved the “problem of my young confusion” by slaying the wonder at lay at the heart of the question. The physics of the answers I got—that rotates around what, how the atmosphere distorts—bled mystery out of the world, turned the world into a machine, and sedated wonder with information. Information is where wonder often goes to die. There are tens of thousands of seven-year-old poets in any large town or small city staggering under the weight of the sheer mystery of ordinary things, it only a few handfuls of forty-year-old poets there shuffling their feet through the gravity of their times, fallen leaves in the gutter as the days grow shorter.

The greatness of a great question is that it can survive any and all answering, and still be left standing after the debates and harangues and

rationalist assaults have bashed away at it. There are no great answers, you could say, but only great questions made greater when their answers are nobly defeated by the awe and mystery of the way things are. Great questions are not problems to solve any more than great feasts are problems for stomachs to solve. They are not lacunae in the web of our intelligence, waiting to be filled with more intelligence. Great questions, given half a chance, *are* our intelligence. Intelligence should not be a siege machine in the efficiency army’s assault on the tower of what we don’t know yet, though in our time and place it is mostly that. Great questions are a proper throne for wonder, and there is much in our life that needs our wonder, and deserves it, just as we ourselves deserve the capacity for wonder that came to us early on but does not often survive our education.

A great question happened to me as a child. I still love it, it is still great to me, and it is still a question: Can soap be dirty? I know it doesn’t sound like much, but there’s something there. You might remember that bar of soap in the bathroom in any public place and say emphatically, “Yes! Soap can be dirty. I saw it.” But if you stay with the question a little longer, you might start to wonder whether the dirt on the soap makes the soap dirty, or whether the dirt has to be *in* the soap somehow to make it dirty. Then you might go further and wonder whether it isn’t in the nature of soap to be cleanliness itself, so that soap will always be clean and dirt will always be on the outside of soap looking in. These are the kinds of things I wondered about as a kid, anyway.

Hope is the soap of palliative care, in a way. Hope is often the tower of sand where most dying people live out their days, staring through a small window down onto the fields of the longed-after things that will come no closer and the hatred and feared things that will gather there instead. Hope is the siren song of anyone who loves a dying person, the conjuring chant taken up in the name of compassion. The preservation of hope is the base

element in any plan made for dying people by the people paid to care for them. It is the root condition for proceeding. That is the conviction of most of us, dying or not. Hope is life loving, and it cannot be otherwise. Without hope, they say, what's the point? And it's always a rhetorical question. In my years at the bedside and at the podium in palliative care, I have never heard hope wondered much about, or challenged, or talked about as if it were anything other than goodness incarnate and the secret ingredient that makes Maslow's "hierarchy of needs" and living and dying make sense.

A few years ago some researchers proposed to test what variable had the most significant impact on physicians' ability to accurately predict the course of their palliative patients' disease trajectory. One of the things they discovered in their test group was that the prognostic accuracy decreased in an "overly optimistic direction" the longer the patient-physician relationship went on. As the physicians spent more time with their terminally ill patients and with the patient's test results and lab work and family and history and hopes and fears and care plan, the physician's estimation of how much more time the patients were likely to have changed apace, and this shift in the estimated time a patient had left was almost always, as the researchers call it, overly optimistic. The doctors consistently tended to grant More Time to the patient, and the patients consistently tended not to live the More Time granted to them.

The physicians' prognostic accuracy seems actually to have been compromised by prolonged exposure to the patient. On the surface at least, that feels odd. If you are a patient, you want the physician to spend a lot of time with you and your chart, believing as you would that more familiarity can only help matters. The physician likely believes the same thing in principle, and time and workload permitting will try to gain that familiarity by putting that time in.

How could prognostic accuracy be compromised by prolonged exposure to the patient? And why does the compromise tend toward granting *more* time to a patient's life? Maybe it is because increased exposure to the patient tends to have the effect of binding the physician more strongly to the patient's views and wishes for his or her care plan,

and maybe this tends to compromise the physician's judgment as to prognosis, to make it more consistent with the patient's wishes. As time goes on the physician's experience, judgment, and training all seem to get hitched to the bandwagon of encouragement, support, and cheerleading the patient in pursuit of what the patient wants. And if the patient is "negative" and has a grim or overly realistic view of what is to come? The physician will again tend toward advocating a more hopeful outlook in the patient, the belief being that only good can come from being realistically hopeful.

The article seemed to strongly suspect that what the patient wishes for is contagious, but I think the dilemma it describes goes a little deeper. Medical training is thorough in most things. I don't think it is very likely that most physicians would confuse their training and experience with their patients' wishes. There is a subtler something going on with this. It is not the *content* of what is wished for—the grail of More Time—that is contagious. The fact that the patient steadfastly wants what is already gone for good, often long after it has gone, perhaps this is the contagious thing. The patient's insatiable desire for what will never be makes the doctor's simple objectivity and prognosis look and feel ineffectual, impotent, even disloyal. Many a physician has been accused of giving up on patients when they attempt to refer those patients to palliative care.

It looks as though sympathy and discernment are hard bedfellows where dying is going on. The consequence of this conflict—I have seen this many times—tends to be that the physician will delay referring a terminally ill patient to a palliative care service. For any patient who is paying attention, this referral is the end of the physician's willingness to go along with the program for More Time. Patients' desire for a close, more personal relationship with their physicians seems often to compromise the physicians' judgment. It challenges the very firmly entrenched belief in palliative care circles that the physician must establish a relationship of trust with a patient prior to being able to "break bad news." Usually that trust depends on physicians clearly aligning themselves with the patients' views and wishes regarding their prognosis, and not prematurely challenging those views and wishes. This "relationship of trust," if it requires time

to be established, is built on the assumption that there *is* more time, and will be. It is also built on the conviction that what the physician knows of what is to come must at least for a while take a backseat to the principle of maintaining that trust. This is an uncommon understanding of what a relationship of trust should look like, is it not? It also should make us wonder: When *is* a good time for prognostic candor? When will the old relationship of trust be challenged by a new willingness to be honest with the patient about what the physician has known all along? Will the patient's hope ever legitimately be undone by the physician's training, experience, judgment, and counsel? Is maintaining hope what the helping professions owe people who are dying?

Years later some research was done on the subject of what patients want to be told by their physicians about their diagnosis and prognosis. It found that patients wanted clarity, precision, lots of information, an accurate prognosis, measured but full disclosure of the nature, consequences, and outcomes of their disease . . . and they wanted their overall hopefulness about their outcome left intact and supported and sustained throughout the process of their dying. Now on the face of it, this can't be done. There are two solutions that I've seen used over and over. In the first, the physician isn't entirely candid about the prognosis. This is generally defended as being done in the best interests of the patient by proceeding with information sharing according to the patient's willingness and ability and readiness to hear it. In the second, the patient is more or less gently prodded into shifting the content of the hope to something more realistic, given the likely outcome.

Doctors and social workers usually invoke a patient or family-centered model of care that places the patient at the center of the care plan as its coauthor and quality-control person. This solution looks concerned and compassionate, and gives candor its proper junior position in the scheme of what the patient deserves. A second solution is to periodically recalibrate the content of hope—the hoped for thing—to compensate for the ongoing failure of the care plan to achieve or sustain patient health. This solution looks discerning, and it recalibrates the patient's wishes by invoking the principle of “realistic hope.”

Each of these solutions, and all others that I have seen in my years in the death trade, accepts in principle and without qualification the presence and the necessity of hope in the work of helping someone die. There is everywhere I look an uncritical willingness to support the hope project, because there is everywhere a belief that hope is inherently good, inherently helpful, and inherently necessary, especially in the face of this most trying of life's travails. Wherever hope is discussed, it is discussed in terms of its content, but rarely in terms of its function. There is strong belief in the palliative care community that a great leap forward has been made when a patient is encouraged to change what he or she hopes for as their dying comes on. Nowhere that I know of is there much discussion of what hope *does* to someone who is dying hopefully. Everywhere hope's function is tied to its content: If your hope is for something that is foreseeable, or possible, however exaggerated your sense of the foreseeable might be, you ought to be hopeful, and that'll be good for you. But what does it *do* to you to be hopeful that way?

The backyard lot of this housing complex had one of those inner-city commuter highways running through it. The drone of tons of metal hurtling through a former river valley was the background sound to everything. When people fought, read, thought, fled, made love, and made dinner there, they did it to the roar of strangers' cars passing through. When I finally found the right door into the place, I thought about what I knew of the people on the other side of it: The patient was about thirty-five, never married and no children, living with her mother only, a married sister in the city, all emigrated in the last five years from the Philippines. Stage-three lung cancer. I guessed a little more: She'd had no time to get well established in a job before she got sick. Maybe she had some kind of custodial, maintenance job somewhere, and maybe she qualified for the government health plan. There likely wasn't much

money between them, or they'd probably be living somewhere else. Likely she was a pre-Vatican II Catholic, and likely this was coming in for some hard service lately. Likely she had a nagging suspicion that coming to North America had something to do with getting cancer, and likely she was awfully bewildered at being in the hands of a high-tech oncology team.

Her mother was very reluctant to let me into the apartment. She said nothing before or after I introduced myself, but when it was clear to her that I wasn't going to get discouraged and leave, she just walked away and left the door ajar. After a little awkward deliberation with myself, I went in. Two wrong turns later I found the lady in question cross-legged on the couch in the living room, in a head to toe purple housecoat, staring intently out the window and away from me. Almost hairless from the latest radiation, quiet, and wearing what she was, she looked for all the world to me like a Buddhist nun. I sat on the opposite end of the couch and told her a little bit about who I was and why I was there. She didn't respond, but continued looking out the window. Somewhere in a bedroom upstairs, a young child cried loudly about not wanting to go back to school after lunch—the only sound in the place besides the highway din. Plainly no one in that home thought I was a good idea.

At times like that I remember a bizarre little event from my student days, and it gives me some leverage with which to negotiate the total collapse of social grace or the utter absence of a shared understanding of anything, not an uncommon experience in palliative care. As part of my schooling back then, I interned in the psychiatric ward of a local general hospital. The place was run by a psychiatrist who had a closet commitment to Gurdjieff, though he never let on how this influ-

enced his work. He took me aside in my first week and told me what a rookie in psychiatry needed to know, concluding with this: "Of all the people that are admitted while you are here, a third of them will get worse no matter what we do, a third will improve no matter what we do, and a third will leave the way they came in, no matter what we do. Your job will be to figure out which third your patients belong to." So things went along: me trying to understand how anyone could come to work seeing it that way. Later I wondered how they could come to work otherwise, such is life in the psychiatric ward in a general hospital. Eventually I was reamed up with a cunning, generous, earthy mentor whose idea of reaching was to drag me around the ward with him and then retire to his office to discuss anything but work to give me a chance to express myself. One day he said, "There's a new admission I have to see, a young woman who had to be restrained overnight. She was pretty aggressive, and she's probably been sedated. She may not be in good shape, but we'll see. Come on."

The woman still had her straightjacket on and stared at the ceiling. It seems that those things are designed to drive their wearers to their wits' end and beyond in the name of calming them down, a Kafka solution to aggressive behavior. We filed into her room, and my boss started to introduce himself. He got three or four words out when this woman, doing a very close *Exorcist* impression, reared up on her elbows and snarled, "Fuck off," with the spittle flying. Without breaking stride my boss saluted her, said "Fucking off," turned and left the room and me standing there.

I caught up with him thirty feet down the hall, awfully concerned about how things went, and asked him how he could say that to someone in her state. He

stopped in the hallway, looked at me and said, "What better response do you suggest? I just took her at her word. I did what she asked. Nothing else was going to happen then. We'll try again tomorrow."

So I wasn't too thrown when the lady from the Philippines wouldn't look at or speak to me. But I wasn't going to put her through too much awkwardness in her own home, and I wasn't going to take much of her time and energy when she clearly had other ideas of how she should spend it, so I went to the heart of the matter promptly. I asked her, "When there's no one here to ask you about your blood pressure and your bowel movements, what do you find yourself thinking about?"

Her answer came quick and assured: "I am very positive and hopeful about my situation."

Most people in my line of work would be reassured by her answer. They would hear a woman who is positively oriented to her circumstance, who shows no outward sign of depression or anxiety, who is acting in her own best interests, appropriately guarded. They would look around for other things to talk about, now that her mental status has been found to be hopeful and forward looking. They might wonder whether there is much more to be accomplished, at least until the woman hit the unfortunate but foreseeable wall of her hopefulness collapsing under the pressure of mounting symptoms and drugs. But to me, an answer to so uncommon a question that comes so fast and so assured doesn't bode well for now and in the longer term.

I said, "Well, that's all right. But I'm not asking how you are doing, really. I'm asking you something more specific, about what you think about. What do you find yourself coming back to and back to in your mind when you're on your own?"

I admit that this isn't an easy question to answer. Neither you nor I would be able to answer this one on the run with any certainty or satisfaction. It takes some serious hesitation and pondering to catch up to what claims you in the times in between life's "got tos" and "going tos." Someone you don't know asks what you're thinking about most of the time, and you may have to think long and hard to figure out what it is. Someone with a terminal diagnosis, though, she knows the code, the propriety. She knows something of what is expected of her. Her next reply was slower in coming, and a bit rambling. It took a minute to take some shape and gather some of her meaning. In summing it up for her best as I could I said, "It sounds as though you are spending many of your days praying. Is that what you mean?"

This too wasn't much of a daring summary. Her old-style Catholicism and her newly acquired and terrifying patient status made the guess about prayer an obvious one. She agreed that she was praying a lot of the time. Here most people in my line of work might translate this as clearly a good thing, and they'd leave well enough alone, being able to check the box on the intake form that says "Religious Affiliation: Yes or No." Prayer in the context of terminal diagnoses is natural enough, among those who still pray anyway, and it would probably be left at that. Instead, I asked her, "If you don't mind me asking, what is it you are praying for?"

Praying is its own reward for praying people, usually, and the news that someone is praying in the midst of a terminal disease process is generally tolerated in the helping trades and thought of as a good thing. But the content of someone's prayer, especially given how intense and private it can be, isn't typically asked about. Prayer is one of those dirty soap subjects. It has inher-

ent merit, it is at the very least its own reward, even among those who don't pray, and it mostly signals to people in my line of work that the dying person has a predisposition to inwardness and a willingness to be reassured. But I am not always persuaded that prayer is the balm it often appears to be, and I'd like it to earn its keep the same way I have to earn mine. So I asked her what she was praying for, and her answer this time was halting, uncertain, a little lost. With a lot more expertise on my side than she had on hers, I summed up her answer this way:

"It sounds to me like you are praying for more time."

She nodded slowly. How could she not be praying for that? You could plot your course across the Sahara, you could do any number of divinations with this unshakable, enduring, and eternal instinct that people with a terminal diagnosis have for praying for *More Time*. That is how enduring, widespread, and predictable it is. Again, most people who receive palliative care have received *More Time*. *More Time* is almost never the balm that people bargain for. It never appears as it did in their hopes and dreams and prayers.

We were coming to a kind of crossroads in our short meeting. I'm with a dying person who is praying not to die, at least not now or soon, who will almost certainly die more or less on schedule and who is dying as we sit there together. This brings up the question, What else *is* there to say about it? I could veer away from where this was surely going and say nothing more about it, or I could keep going and meet her at the place where prayer and prognosis was taking us.

I said, "Okay. Last question, and then I'll leave if you'd like. It's not an easy question, but I'm going to ask it anyway, and I hope you can forgive me for ask-

ing. How would you know if your prayers had been answered? How could you tell?"

As I said, I went to the heart of the matter, and the heart of the matter for a religious woman with cancer is, Where do her beliefs meet her dying? Do they meet at all? Prayer *in extremis*, pared down, is usually part supplication and part demand. At such a time, though, no one I've met prays to stop praying or to get to the end of their prayer. A rosary is a circle of beads after all, without end. Praying people pray to keep praying, if for no other reason. This specific prayer for *More Time* when you're dying, though, is a very tricky thing. If it happens at all, when does it begin? Does it look like all the other time before it, or does it have a different way altogether? What is the sign that it's happened? How *would* you know if your prayers had been answered? What would change?

This was the first time she looked at me since I had sat down. There was none of the equanimity from her first answer, none of the praying person's contentment or the religiously affiliated person's sense that they know what is going to become of them. There was a raw, unalloyed terror in her eyes; that was all. I knew her rickety certainty about praying was swaying, and I knew too that it was a terrible thing.

I said, "I know this is a hard question. It's almost impossible to answer. I've thought about this a lot though, and if it is okay with you I'll tell you two answers that I've come up with." She gave me something like a nod, the kind of acquiescence that people with no real choice give, and so I continued.

"Let's say that against all your upbringing and against your own inclinations you pushed the oncologists until they finally gave you a number. Let's say they told you,

though they didn't believe it would do you much good to know, 'Well, probably three to nine months.' So you stumbled out of that office and into the light of day with this news, with this sentence in your ears—"Three to nine months"—and nothing any longer looked like it did. Not the sidewalk or the road, not the trees or the people or the light itself, none of it looked as solid, and none of it looked like it included you anymore. Somehow you made it home. Once you were inside, maybe you went right to the kitchen, because in the kitchen is the fridge and on the fridge are the magnets and under the magnets is the calendar. And maybe you didn't know which date to flip to: Should you want the shorter estimate, the one that gives you the least likely time, so that the More Time can start sooner? Should you want the longer estimate, to give you more time to pray for the change you're praying for? You probably are a positive person and so you flipped to nine months, not three, and you circled the day with the yellow highlighter. And that's your goal, to get there. And if you get there, if you are still breathing by means normal or mechanical, *that* will be the sign. More Time will start that day. From that day on your prayers will have been answered.

"What will it be like, to see that day? You'll be able to move and speak and feel like a person who was worth the trouble, who made the cut, when you know there are lots of others who did not and will not. You will be one who was heard and deemed deserving, whose prayers have been answered. It'll be a hallelujah time, then. But until then, what? Keep praying, that's what. Keep praying for more time, like you and your friends and your congregation have been doing. Keep praying to see that day on the calendar.

"The other possibility, strange as it might sound, is that your prayers have already been answered, and you missed it entirely. Pretty hard to imagine. Not impossible, though, not at all. What if the fact that you and I are here talking about it is all the proof you're likely to get or need that you are in the middle of your More Time? What if this is what More Time is, nothing more and nothing less special than this? If that's true, then you could already *be* the person whose prayers had been answered, instead of being the person waiting to find out, and you could walk and talk and feel like someone who has been heard and found worthy. And you could feel like someone who made it, a prayer-answered person, today.

"And if your prayers for More Time have been answered already, would you go through your days any differently?"

This was an awful lot to take in, and our visit didn't last a whole lot longer. I know that she thought about this question about praying for More Time, about not knowing when it starts, just as I have many times thought about it since. It isn't a comforting thing to wonder about, but often at 3 a.m. it is the only thing to wonder about. No one who is dying is likely to ask you to help them wonder about their prayers, and I don't think waiting for them to ask you to do so is a fair thing to ask of them. Sometimes you have to wonder aloud whether hope is all it is cracked up to be and wait for the pieces to fall. Maybe you'll get to be there when they fall.



You know how it is when you have a mortgage. Many things that once were possible are no longer possible. Once you did things that now, for good reason, you no longer will do. You will put things on hold. You will

wait. You will do without. You will do less with less, and all of this you'll do because the mortgage gives you some guarantee that the sacrifices you are making will come out well in the end. You live *in* your mortgage, and because of that one day, all going well and you don't sell, it will become your house.

Hopeful people generally have their one good eye on a future they imagine; the more jaundiced eye on a present they mostly tolerate, and both eyes on a past they have a hard time remembering well and letting go of. Hopeful people do not as a rule hope for what they have. They hope for what they do not have. They hope for what they once had to come again. Hopeful people do not in their hopefulness often vote "yes" to the present. They vote for the future. Even those with a greater agility of hope, who hope for more of what they have, they are still voting for a future in which to have it.

Here is the connection: Hope is a mortgage. It is not *like* a mortgage: *It is a mortgage.* Hope is a mortgaging of the present, for the sake of some possible future that might come to pass and just as likely might not. Being a hopeful person with a terminal diagnosis means that, like those doctors in the study, you are in some mysterious and compelling way not allowed to know what you know when you are dying. In a death-phobic culture like our own, *knowing you are dying is not as healthy as hoping you aren't dying while you are.* When hopeful people are dying, and when dying people are hopeful, they buy a house on a street called Not Now, in a town called Not Yet, according to a Freedom 55 investment plan called Anywhere but Here. They become fighters, and the obligation they hold their families, friends, and caregivers to is that there be nothing but positive, upbeat, hopeful talk around them, no matter the diagnosis, prognosis, symptom buildup or failing strength, phantom capacity or fugitive alertness, until they themselves give the unequivocal signal that they have given up hope.

As long as you are hopeful, you are never in the land you hope for. If you bargain for More Time, you never live in the land of More Time. Your more time is spent bargaining or praying or hoping for More Time. No one seems to hope for what they have, and hopeful dying people rarely get the More Time they hope for; no matter how much More Time they

get. This understanding was inside the questions I was asking the Filipino lady. What you want rarely looks like what you get, but it almost *never* looks that way to hopeful dying people. The questions I asked her weren't taunts, not some unbeliever trying to take a dying woman's faith down. I myself am a praying man, but on my good days, when I know what I know, I am not a hopeful man. No, these questions were one way I had of asking her to consider that her unquestioned faith needed to earn its keep, that her hope for More Time owed her something other than More Hope.

The bargain for More Time is a gamble for More Life, in oncology, in palliative care, in any foxhole. More Life is the reward of More Time, so the hope goes. But More Life at the end of your life is lived in the distinct, ample, palpable presence of your death, and the chances are very good that if you are a dominant-culture North American you have not lived your life in the presence of your own death much before your diagnosis, if at all. So your More Life is asking something of you that no one warned you about, that no one around you probably understands or has thought much about. It is asking something of you that you have not much experience with, something that will probably show you to be the inelegant amateur that you are in this the epic waning of your days. Your More Life, it turns out, includes More Death, a lot More Death than you ever imagined could be in one life. As you try to live this thing that was to be its own fine reward, you find that More Life is mostly More Death. They were quick to offer you chemotherapy or radiation for your More Life, but there aren't many offers teaching you how to have More Death.

The doctors and the psychiatrists and the counselors are not unkind in this, certainly not knowingly or purposefully. They are not people living in a place called More Life withholding something from a dying person living in a land called More Death. They don't have some secret strategy of support. No, paid therapists and physicians and volunteers and families and dying people are mostly *hopeful* people in the time of More Death, and hope has often numbed many of them to the understanding of what More Death means. Hope is contagious, and it is to me a kind of obscurity at a time like that. Hope is an anesthetic of the spirit. Many people are fearful that if they speak of dying in a clear way "at the wrong time" they

will disarm dying people at the very time they are supposed to be fighting. I've seen many times that family members and health care workers secretly believe that to speak of dying is to approve of dying, that grotesque Word Voodoo that mures most of us when dying is in the room. And so the knowledge of the thing goes AWOL, and we wait for the rip tide of symptoms and diminishing energy and lucidity to dare the dying person to learn how to do it with whatever is left of their capacity and their willingness to learn.

Hope almost always makes sure that it is too late to learn how to die for dying people in a death-phobic culture. That is what it does to them. Turning away from learning how to die well in the name of being hopeful, dying people consume probably as many antidepressants and as much anti-anxiety medication as do late-middle-aged people who have lost whatever they once had of a feel for why they are alive. Somewhere in the Mall of Hope—and research will someday show this to be so—this culture is incubating a considerable demand for physician-assisted suicide and for terminal sedation among dying people that cannot be explained by a concomitant increase in their symptoms or pain.

How could it be otherwise, then, that dying people and the people who love them and the people paid to care for them often understand dying as nothing more than a challenge to endure, as the low-grade curse of the passing of time when the prayers and the gambles for More Time have come to pass?



More extraordinary than Elisabeth Kübler-Ross's ideas in *On Death and Dying* by far was the unqualified, mass-market embrace these ideas enjoyed soon after they were published and continue to enjoy across the dominant culture of North America and beyond. Wherever I teach there are large numbers of people who can quote "The Stages" without ever having read the book, sounding as though they are reading from the book when they do so, many of them not knowing that there is a book that these ideas come from. The ideas in *On Death and Dying* were timely, but does

that account for the massive influence they now have? I don't think so. In unpublished research, Dr. Michele Chaban has argued persuasively that Kübler-Ross's ideas were derived largely from her early work with people who had escaped a nightclub fire that had killed others and who were subsequently experiencing what we would now call post-traumatic stress disorder. Kübler-Ross seems to have identified the PTSD sufferers as people who had "nearly died." People who are close to dying people are not nearly dying themselves, though, and that is one dilemma in the scheme. The patients she worked with were never dying. They were exposed to what killed other people, and were traumatized by that, surely, but it is very possible that *they were not traumatized by dying*. Kübler-Ross appears to have applied these ideas about coping with trauma to the experience of "nearly dying," and she found what to her were compelling similarities. So it seems were born the famous five stages and the discussion around them. Kübler-Ross seems to me to have counted on the fact that dying was inherently a traumatic event, that it was in the nature of dying itself that the trauma was to be found. She then seems to have generated a strategy for purposeful coping—the five stages—to manage that trauma.

But ask yourself whether dying is universally traumatizing, across all cultures and times. It is not so. It is not so even here, where it is so rampant, and I cannot credit *On Death and Dying* for these exceptions. Dying is traumatizing when it is happening in a place and time that will not make room for dying in its way of living. It is not dying that is traumatic; it is dying in a death-phobic culture that is traumatic. The continuing extraordinary popularity of some of the ideas in *On Death and Dying* are partly a result of the fact that the author's assumption of the trauma of dying has found easy recognition and acceptance among people who have lived a death-phobic life and believed likewise. This death-phobic culture recognizes the trauma unto death sold in the book in its own experience. Look carefully in the tables of contents in palliative care textbooks, read the mission statements of palliative care agencies, study the Best Practice Manuals of palliative care associations. Explicitly or otherwise, you will find that most of them accept without pause that dying is trauma. What they prescribe is management strategies for that trauma, for the physical

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and metaphysical consequences of that trauma. Cope, Hope, Dope: the trivializing trinity, the barstool for dying people to teeter on in a place that will not tolerate death.

So, a culture that sells hope to dying people is selling them anesthesia and management. Hope, as much as anything else and more than most, traumatizes people at the end of their lives. Hope, like any good shuck and jive artist, sells itself and its absence as the only two options in town. In our good binary oppositional style of argument and contention, many of us imagine for dying people and the people who love them only hope or hopelessness: either the faint possibility that things can be otherwise or the withering misery of being pinned by the brute fact that they will not be. In a death-phobic culture, dying is not a credible outcome: Dying is giving up, and hope is refusing to give up. In the health care system of a death-phobic culture, dying is where the health care ends, because dying has no place in any understanding of health. We have strategies for not dying instead, and hope is a large part of the creed that informs those strategies. It can make you crazy, being hopeful, and when you are dying in our part of the world it often does.

One alternative is first to wonder our way out of this false choice that we are offered when we are dying. “Hope” is not life, and “hopeless” is not death and depression. Hope is very often a refusal to know what is so, and steadfastly it is a refusal to live as if the present moment is good enough and all we really have. Hopeless is the collapse of that refusal, and it looks a lot like depression. The alternative is to live your life and your dying *hope-free*. If you are willing to seriously wonder about what being hopeful has done to you, what it has obliged you to know and not know, how it has hamstringing the caregivers of dying people and their loved ones who are only allowed to know what they know when they are not with them, then being willing to be hope-free begins to look more like a subversive move toward lucidity. Living and dying hope-free: that is a revolution. The chance to die that way is what dying people deserve.