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In the Beginning . . .

For dust thou art,
and into dust thou shalt return.

—Genesis 3:19

Dust *n* Old English *dust* (probably about 725 AD), cognate with Old High German *tunst*, meaning breath.

—*Chambers Dictionary of Etymology*

breath [A.S. *breath*] 1. The respired air. 2. An inspiration

—*Stedman's Medical Dictionary*

Dying has a bad reputation. Most people imagine dying as The End. In this literal way many people conflate the two ideas, thinking of dying as death and not the life before it. Either way, dying and death are sad and bad. In other words, many people believe that nothing good can come of dying. But this is very much a cultural understanding—and a limited and narrow one at that. This perspective is not found in the rest of nature. As far as we can tell, trees and rabbits do not view the threat of death in these ways, yet they react to the threat of death in similar ways to us. To understand why a dying human being should have anything in common with a dying tree, we must start at the beginning of life and not at the end. We must start with an understanding of our own mortality that links our basic reactions to the threat of death to what we are made from—organic, cellular life. No holistic explanation of our inner reactions to the threat of death is possible without this biological and social context.

Furthermore, because most readers often imagine dying as awful, terrifying, and self-evidently life extinguishing, we need to reframe this view. This requires understanding how different dying and the threat of death are, depending on one's perspective. The perspective of the participant is not that of the onlooker. The perspective of the dying animal and that of the predator have little overlap. In this way, for both animals and for human beings, dying has unique dimensions of perception and experience that are commonly obscured, even obfuscated, by onlooker attempts to describe it.

Becoming clear about our so-called natural reaction to death, and the role of different perspectives in understanding a personal response to death, is also key to understanding why our academic and clinical literature on death and dying contains so much confusion; why certain dark and pathological myths have risen to explain our experiences of dying—and both fill and terrorize the popular mind; and why the vast majority of people—certainly everyone outside biology and anthropology—think there is not, nor can there ever be, anything good to say about the human experience of dying. For all these different reasons we first need to look to the beginning of life and not at the end.

The Nature of Dying and Death

From the beginning of life itself—from the first unicellular organisms to the evolved complex animals—life has recognized and used dying and death as an integral part of its inner workings. Construction and destruction, living and dying, go hand in hand as seamless processes that require each other. To live cells need to destroy smaller chemicals and rearrange them for their survival. Larger animals need to destroy other organisms, usually plants, sometimes other animals, and rearrange their cellular material so that they can use them as an energy source and live on. The purpose of this process in the food chain is generally viewed as positive. After all, if you don't eat, you don't live.

However, few people spare a thought for the food—the living things that larger, stronger living things eat. Fortunately for us the biological sciences rarely share this blissful denial about dying, so we have a considerable amount of work that examines what organisms do when threatened with death. Most of that literature concerns how animals—bacteria, trees, bees, dolphins, or antelope—defend themselves. Most people understand that

the main defense mechanisms center around fight-or-flight responses. Cells harden themselves, develop chemical forms of repelling their threat, later develop specific cells to deal with threat, and later still develop specific physical talents to deal with threat. Humans, at the top of the animal kingdom, even develop technologies and counterideas to deal with threat.

In multicell organisms the two-response fight-or-flight strategy to respond to threat continues to evolve into at least five or six responses. For four billion years we have been coming up with ideas about how to survive, breed, and raise our young. The biologist H. S. Bracha summarizes these as freeze, flight, fight, and then feign or fright.¹ Freezing is the act of not moving—a clever strategy that exploits the evolution of the visual cortex and retinas of many carnivores, which primarily detect movement rather than color. Hiding is also part of this initial response to the detection of a predator, as is fainting. Fainting has been protective even in humans as an adaptive behavior of many noncombatants—females, children, and young men. This leaves an aggressive predator to focus on slow, wounded, and otherwise still moving prey. Flight—running away—and fighting are the best-known responses to threat. Fright or feigning is a response most famously demonstrated by the possum—you act dead so as not to incite the predators to kill you straight away, and as soon as they loosen their grip, you make a crazy run for it.

It is important to remember that these defensive strategies for survival are not either/or responses but can be, and often are, used by all animals at different points of an attack and defense cycle. In fact, many animal watchers believe that these defensive maneuvers occur largely in sequence.² The feign/fright response, also commonly called the tonic immobility response—is commonly described as a terminal response—a last reaction when nothing else seems to be working. Each sequence of response is based on “the prey’s perceived decreasing distance to the predator.”³ In other words, if you are a long way from the predator, freezing or hiding is a good first response if the predator hasn’t noticed you. But if a nearby predator has spotted you, running makes a hell of a lot more sense. If you can’t outrun the predator, it makes more sense to at least try to fight it out. Finally, if you are clearly losing, pretending to be dead can slow up or stop the predator from tearing into you, perhaps just long enough for you to dash to safety. This last response is an ancient and useful reaction in the animal world, found in fish and insects as well as in mammals.⁴

These different and sequential tactics are used as defenses across the animal kingdom—in deer, whales, and primates, to mention three random examples.⁵ Thus the reaction to the threat of imminent death involves

1. More than fight or flight. Fighting is not the only way to defend—at least five or six defenses are available, and some don't appear to be fighting responses, but that doesn't make them less effective.
2. Different reactions, sorted by order or priority, depending on the perceived distance of the threat.

In the multicell animal world, just as in the single-cell animal world, predation is a primary selective force driving evolution, and much of an organism's biology may represent adaptations to reduce the probability of detection and capture.⁶ These range from the complex internal stress response, such as the commonly described cascade of neurotransmitters, hormones, peptides, and cytokines in the blood stream that warn all cells and tissues of the presence of a threat, to the more obvious: inherited colors, running and jumping abilities, hard-shelled and spiny skins, or appalling smells, and surprising behaviors that protect animals and give them their distinctive shape and special presence in the world.⁷

Admiring a desert cactus is difficult without also understanding how the many spines on these plants have evolved to both protect them from being eaten and to help capture the precious little moisture in the desert landscape. Admiring the speed of deer or dolphin is difficult without also appreciating how such sleek maneuvers and shapes have evolved to evade predators in an environment full of carnivorous competitors. Thus fear and the various defensive strategies that we use to counter the threat of death have not only purpose but positive purpose for dying organisms. Fear helps alert an animal to danger. Then fear assists in mobilizing strategies that either save its life, prolong its life, enhance its abilities, or spare the animal from being overwhelmed by terror at the point of death. Fear and defense are positive experiences for organisms threatened by death. Dying and death also play positive and purposeful roles for living in another way.

Cells (like human individuals and groups) will commit suicide for the greater good.⁸ There are a lot of examples. Snakeskin, cocoon casings, and autumn leaves are just three of the most obvious organic examples of what

is called programmed cell death (PCD).⁹ PCD is a way that organisms actually use dying and death as a purposive tool for enhancing an organism's life. Programmed cell death was first observed in amphibians, then insects, and then all life forms. PCD helps sculpt structures (such as the little holes and serrations in leaves), deletes unneeded structures (such as leaves in the dead of winter), controls cell numbers (to make way for fresh energy-producing incumbents), and eliminates abnormal, misplaced, or harmful mistakes (such as cancer cells). Any attempt to stop PCD will likely lead to major deformities—or worse—for any animal.¹⁰

At this point in our discussion we can draw two conclusions from the defensive reactions of animals to the threat of death *and* from the way that cells use dying and death to enhance their lives. First the biology behind experiences of dying and death usually reveals that all living things have a positive purpose. If we move from a predator's point of view and examine how prey defend, we can easily see the life-enhancing reactions within the responses of prey. Dying, up close and personal, displays and embraces a vast array of self-preserving and self-enhancing processes and experiences for the threatened animal. Second, organisms also commonly use dying and death in cellular processes to enhance their life—by being part of self-building and self-designing projects, and in affirming and enhancing their other life functions. But if these positive purposes are so pronounced, so obvious in the biological and social life of small organisms and big animals, and have been around since the beginning of life itself, why is the examination of the dying experience so silent about them in observations of human beings?

Perspective Is Everything

When we look at the emotional picture of dying months before death actually occurs, we often get quite a different impression than when we look at the same situation some minutes before death occurs (“different reactions are sorted by order or by priority depending on the perceived distance of the threat”). In this way we sometimes conflate an onlooker's view of dying (quite distant from the dying) and the dying person's view of dying (near-to-imminent death).

For example, imagine a man who is being attacked by an escaped tiger at the zoo you are visiting. Imagine the horror of seeing that man tossed about in the jaws of the attacking tiger. Imagine your fear—for your own safety and those who happen to be with you. I will wager you cannot avoid imagining the terror that the victim himself must surely be experiencing. Now read how David Livingstone, who survived the ordeal to write about it, experienced being attacked by a tiger:

Growling horribly close to my ear, he shook me as a terrier does a rat. The shock produced a stupor similar to that which seems to be felt by a mouse after the first shake of the cat. It caused a sort of dreaminess, in which there was no sense of pain nor feeling of terror, though [I was] quite conscious of all that was happening. It was like what patients partially under the influence of chloroform describe who see all the operation but do not feel the knife. This singular condition was not the result of the mental process. The shake annihilated the fear, allowed no sense of horror in looking round the beast. This peculiar state is probably produced in all animals killed by the carnivore; and if so, is a merciful provision by our benevolent Creator for lessening the pain of death.¹¹

Raymond Moody, a physician who wrote one of the first modern books on the near-death experience, quotes a man who recollected his experience of a severe head injury. The man's vital signs were apparently undetectable at the time, but the man himself describes something quite transforming and counterintuitive to an observer. "At the point of injury there was a momentary flash of pain, but then all the pain vanished. I had the feeling of floating in a dark space. The day was bitterly cold, yet while I was in that blackness all I felt was warmth and the most extreme comfort I have ever experienced. . . . I remember thinking, 'I must be dead.'"¹²

The feign/fright or tonic immobility response is clearly dominating the responses of both men, who are—at least from their bodies' physiological point of view—clearly in the grip of a serious, close-up, life-threatening situation. No chance to run in these cases, say their bodies, so let's try faking it—and their physiological mechanisms kick in, whereas Livingstone's companions started firing bullets at his attacker and in Moody's case study the bystanders began frantic efforts to resuscitate the man who suffered the

severe head injury. Either way the fight has begun on both sides—the observers who are fearful, even panic stricken, and the considerably less anxious victim of the mauling or accident.

Hundreds of cases like the one I have just described exist in the animal and human worlds.¹³ Single cell or multicell, dolphin, ape, or human, the body will gear up to save us however it can. However, what makes human beings the most complicated creatures on Earth is that we don't have to wait for an attack or a close threat of death to react to it. Unlike animals and plants, we anticipate death, which means that the number and complexity of potential responses are themselves something of a modern biological and cultural miracle (“fighting is not the only way to defend”).

Most writings about dying take the onlooker's perspective. This is the literature we often see from the health-care professions. Some writers do not have even this kind of experience, and their texts are the product of mere speculation about dying, with little or no experience of the process. Many people, for example, have little or no experience of seeing others die and hope that they will live a long life and die quickly at the end. A popular fantasy might be that they will die in their sleep at the age of ninety-seven. Most people do not want a dying that entails conscious experience, even for a few hours. They want their own dying to occur in a dash, preferably when they are ready for it. Or, as Jean-Dominique Bauby so eloquently put it:

The kangaroo escaped the zoo.
 “Goodbye zoo!” cried Kangaroo. . . .
 Cleared the wall with one clean jump,
 Leapt across with a great big thump.¹⁴

But with so little prospect of such a clean and quick exit in reality, we have instead become obsessed with a collective picture of prolonged dying that has instead made for grim onlooker-driven reading. For most of us dying *will* take a while, at least a few minutes and probably much longer. In a modern and affluent world where most dying is the outcome of chronic illness—from cancer, circulatory diseases, geriatric diseases, and neurological disorders—dying will take time for most of us. Furthermore, our modern medical technology now ensures that whatever serious life-threatening or life-limiting disease we do have will be discovered sooner rather than later, leaving most of us with having

to come to terms with that knowledge well before we are symptomatic. Given the epidemiological and technical aspects of modern death and dying, now is probably an opportune time to ask whether human dying really is so horrible.

What Is Dying?

Although most people think of dying as the final moments of someone who is reclining in bed, perhaps dying from cancer, the experience of dying is both broader and more complex. A number of medical, social, and psychological dimensions of dying need to be considered before we launch into an examination of the dying experience.

First, dying usually takes time. Dying is not only the last few minutes of a person's life. Chronic life-threatening or life-limiting illness gives many people a sense of their own ending some months or even years before their final ending on their deathbed. This means that during this long period a significant amount of their emotional and social conduct and experience will be devoted to thinking, feeling, preparing, and changing their attitude toward life because of this new knowledge. Because of this reorientation, and these changes in their life, the entire length of this experience needs to be considered part of the experience of dying.

Second, people with serious and advanced disease die, as do those with a serious and advanced injury, but these are not the only forms of dying. Other forms of anticipating and acknowledging the imminence of one's death arise from experiences of execution, death camps, or suicide. Being on a sinking ship or a doomed flight, or working in a mine that collapses are other ways that people commonly experience dying.

Third, dying may not be related to events, such as illness, accident, or state decree, at all. The experience of dying may be insipid and gradual, as it often is in advanced aging. Yet this gradual experience of seeing oneself die may follow many of the major social rituals, thoughts, and feelings associated with other forms of dying—will making; financial preparations; physical, social, and psychological defenses and adjustments. Gradual dying may entail the suffering of event-related dying but over a longer period. Aging and dying, for example, can begin to blur into one experience. As a seventy-year-old woman observes about her own predicament:

One doesn't just die all of a sudden. It is a process and one we may be conscious of for the last ten or twenty years of our life, which if you think about it, may be a quarter or more of your lifetime. I find myself wondering why this is not more talked about and why it has not become the common knowledge of our lives. I am self-conscious in writing this. For after all, no one speaks of dying until they have only a few months or weeks or hours to live. This is society's definition of dying. It asks that I deceive myself and others about my daily awareness that my body is using itself up; it prevents me from calling this process by name for myself and others.¹⁵

In all these ways, dying is not an event, is not to be solely identified with illness, and is nearly always an experience that takes some time. Because it takes time, this personal experience is subject to change and complexity, which leads me to one final point.

To gain a reliable picture of dying staying close to accounts of dying from the dying themselves is essential. If we stray from the dying person's account, we cross quickly into the more unreliable, sometimes confusing, outlook of caregivers, onlookers, rescuers, and the invariably disappointed observers of dying. This we do not want to do because, as we have seen, the current picture of dying provided by these sources looks so grim. We are striving here to explore a somewhat more balanced portrait of dying, one that resembles the more positive purposes of dying conduct we see in the natural world.

Dying should be defined as the personal expectation and acceptance of death as an imminent event. This is substantially different from the philosophical idea that death will come to me one day. Rather, for dying people death is either imminent (on a specific date or time—in the next few minutes, hours, or months) or it is immanent, that is, the date may not be known, but the person is aware that death may come at any time.¹⁶ Immanent death comes from a sense of an ending rooted in the conviction that life is being lived in the end times—as it is for those of advanced aged, the seriously suicidal, and people in death camps.

Of course, readers with a preference for precise theories and definitions will object to this rather relaxed definition of *dying*, arguing that it could fit many other people who may not really be dying. For them I have a couple of replies. First, the identity of dying is a fluctuating and context-dependent one. Just as being a mother is a fluid rather than a fixed identity, so too is dying.

One is a mother when interacting with one's own children, sometimes with other people's children, but not even always in these relationships. Sometimes a mother can be a friend to a child, especially to an adult child. It depends on the circumstances. A mother is rarely in that role or expresses the ways of a mother in the workplace, or in bed with her partner, or she would be widely viewed as acting inappropriately. Identities are context dependent. Sometimes they are in the foreground and at other times in the background of a person's psychology. This is exactly the situation with dying. However it comes to the fore, it is nonetheless always there, and this makes it a quite substantially different psychological experience than a mere intellectual view of mortality.

Second, a broad definition ensures that most eligible people are included. This means that some ineligible people might be included, but this doesn't matter much because some people, at some times in their lives, may find their experience shares some characteristics with the experiences of people who clearly are under mortal threat. Conversely, people have thought that they will die—they feel and act like it for a long while—but then they go on to live long lives. These cases too should not be excluded because we are not embracing the destination of dying (death) to the exclusion of the process we are most interested in (living with dying).

If we define too tightly, we risk excluding people who have significant experience in common with dying people, even for a short while. Thus it is best to acknowledge that all our major understandings about life can be fuzzy at the edges and therefore overinclude rather than insist on conceptual precision. Such fine technical precision seldom exists in real life. Wielding it with passionate academic gusto often results in an equally misleading exclusion of people who have a genuine connection with the experience currently under our gaze.

Rediscovering Positive, Purposeful Behavior in Dying

We, like all organisms, use death and dying, in the form of programmed cell death and the defensive, aggressive, impersonal cycles of a food chain, as part of an affirmation, building, or enhancement of life tasks. Taken together, the physical, psychological, and social processes of dying are life processes and always have been. They are every bit as functional and important as the

creation of autumn leaves or the animal need to grow and feed from grasses or algae. How we feel about dying has to do with dying's way of sharply focusing us on our life purposes and living tasks at this new juncture or point in our lives. The prospect of death forces us to think about what role we will play, must play, or have played in life.

The life inside all dying organisms always suggests a specific purpose or meaning for that particular life, for that particular species. Trees use cell death in their leaves to rationalize the effect of drought on their water supply. This is often an evolutionary biological function. The process of programmed cell death in leaves, for example, reflects a set of internal directions—a type of knowing that is embodied in their genetic codes—for what role they will play in the matter of plant design, seasonal changes, and hard times. Skin cells of a snake, for example, know their role when they die—they will help reveal the new life beneath them. The defense reactions of animals to an external threat of death are designed to enhance and affirm their lives, not speed up their extinction, not make it easier for their predators.

For human beings, however, such biologically coded functions are not given, not programmed, not consciously or instinctually inherited, and certainly not easily and consciously understood. Such meanings—like the meaning of *fighting*—are not something we take for granted. Instead, we must discern for ourselves the positive function or meaning in dying.¹⁷ The meaning of our death, like that of our lives, is not preordained by our organic or genetic nature but instead is commonly divined by our conscious effort, reflection, or through review of ideas we inherit from our society and cultures.

We try to make sense not only of biological decline but also the changing inner geography of ourselves, which is forced upon us first by the push of significant suffering, fear, and sorrow and then by the pull of internal reviews of our lives—and our judgments of what we see there. We ask: Who did I become in life? What will I leave for others? What can I, or others, see as the story of my life? Is there a reason for anything here? What's the point of all this trouble? What was it all for? Each of these questions can entail major feats of personal story construction. These stories are about the attainment of a personal truth through the satisfaction of two urgent goals—understanding the purpose and meaning of one's life, and making sense of the ending of that story. As I will attempt to show in the pages that follow, the challenge of understanding our own story is behind every dying moment of every dying

person. This understanding is sought by people with months to die, and it can and has been on the lips of those who have taken their last breath—their last inspiration, a phrase true in both literary and medical senses.

These are the experiences and meanings I will attempt to describe and explore in this book. I do not claim to believe that these are the *only* experiences of the inner life of dying people, but they are certainly among the most important and widespread ones within the different types of dying experiences in the modern world today.¹⁸ The personal experiences and meanings I have chosen to highlight in this book are derived from the themes that dominate the concerns of the different literatures about dying across very different fields.

Sadness and loss, for example, are a dominant theme in the palliative care literature but not in the more transformation-focused literature on dying commonly seen in trauma and near-death studies. The theme of courage, to use another example, is strong in military writings about soldiering and dying but not so much in the fear-, hope-, and resistance-dominated literature of cancer and cancer survivorship. Again, waiting is a dominant concern of those about to be executed, just as review and reminiscence feature strongly in the literature on aging. These biases alert one to the omissions, the overlooked, the underdescribed in the overall landscapes of our understanding about how we die. Taken together, all these core experiences provide us with a more complete and balanced understanding of how dying people aspire to self-preservation and how this purpose manifests itself across a diversity of medical, political, and cultural circumstances.

Overall, I will showcase two principles that I have condensed from the biological and cultural approach to death. These are, first, that fear, fighting, and fleeing, although natural initial reactions to approaching death, often give way to a far wider array of more complex self-preserving responses in humans. We frequently cannot escape or control the powerful physical impulses associated with threat or with loss or deteriorating bodies. This surprises many people who die, most especially those who forget or take for granted their physical machinery and its deeply ingrained and ancestral reactions, reactions that go to the very heart of what it biologically means to be alive.

The exact shape of these early reactions, however, and the emergence of other subsequent reactions are best understood as dependent on our perceived distance to the threat of death. This explains the common divergence

of reactions found between victim and bystander, or patient and caregiver, or early responses to death by dying people and their later responses. This is why we must stay close to the voices and testimony of the dying themselves in any serious examination of the dying person.

This is also why we need to look at dying over time and not single out any one instance, such as what we might witness or not witness at the deathbed. We need as holistic and as total a view as we can obtain and not be deceived by apparently dreadful or happy time-specific scenes of dying. We need to keep a long view of dying in our minds when we read the chapters that follow, because dying often takes time and we should appreciate the complexities, paradoxes, back-and-forth movements, and surprises embedded in that journey.

Finally, my examination will illustrate one other important characteristic of the widely diverse reactions to dying that human beings display. Despite many similarities and differences in how we and animals defend against threat, the conduct of dying humans mirrors the dying of all other organic life forms in one unshakable and unmistakable way: dying always seems to have a purpose that is surprisingly positive; it is commonly life affirming, life building, and life enhancing. This is not an assertion of New Age or wishful thinking but rather a reasonable interpretation of the voices of the dying themselves.

And although onlookers' experiences of loss or terror, and predators' own experiences of domination and consumption, always seem to dominate the meanings of death, these themes seldom have such singularly negative and narrow meanings for the dying person. Instead, dying people commonly report a diversity of positive themes and meanings. In fact, existing studies of the human dying experience suggest that the road to death tends to erode habit, pretense, preconception, and even fear in one's usual character to reveal deeper and novel experiences in personal direction, positive purpose, and social intimacy.

Whether the dying occurs quickly or more slowly, this orientation is often the result of renewed outlooks and commitments, fresh inspirations, and new experiences within what is commonly a challenging, always strange, and ultimately unknown final journey. Although this brief observation might seem paradoxical at first, even radically counterintuitive to many readers now, my aim is to draw attention to these widespread elements of the inner life of dying that seem to point so unequivocally to these surprising conclusions.

2

Suffering—Enduring the New Reality

I did not know what to say to him.
I felt awkward and blundering.
I did not know how I could reach him,
where I could overtake him
and go on hand in hand with him once more.
It is such a secret place, the land of tears.
—Antoine de Saint-Exupéry, *The Little Prince*

Antoine de Saint-Exupéry was a French aviator, adventurer, and World War II pilot who experienced more than his fair share of plane crashes. He once downed his plane in the middle of a desert in Africa, and, while frantically making emergency repairs during his desperate wait for rescue, he encountered the little prince. Later he would write about this little boy in the now world-famous children's story of the same name. We will never know who the little prince was—an imaginary invention of a little boy from another planet dreamed up as Saint-Exupéry went about his repairs—or perhaps something else, a young spiritual being based on a character the pilot thought he encountered in the desert. Certainly, when one reads *The Little Prince*, Saint-Exupéry gives no clue to the answer. In his autobiographical writings, and his media interviews about his many exploits, he often told strange stories about altered states of consciousness, inexplicable encounters with mirages, dreamlike figures, or conversations with beings unseen by others during their mutual exposure to the terrible heat of the desert, after serious crash events, or in periods of great isolation.