

**Our Changing Journey to the End:
Death, Dying and Bereavement in 21st Century America**

Foreword

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In accepting the challenge to write this Foreword to *Our Changing Journey to the End*, I have had the chance to reconsider my own thoughts and strategies for dealing with matter of death, dying and bereavement. At the end of the last millennium I attempted to lay out these thoughts in an essay on the place of science along that journey. Here, I am sharing them with you, but in the sharper light shed by them after another dozen years of life. I hope these reflections will serve to provide a new and useful context for the astounding diversity of contributions to these two new volumes. Also, as the current Director of the University Seminars at Columbia, writing this Foreword allows me to properly thank my colleagues and predecessors for their wisdom and foresight in preserving this remarkable institution over many lifetimes.

In 1905 Columbia University built a magnificent brick and limestone palace of science, Schermerhorn Hall, for its new and expanding departments of geology, botany, and zoology. Carved on its facade is the inscription “Speak to the Earth and it will teach you.” To someone who has studied the Bible, whether the Jewish Tanakh or the Christian Old Testament, this line from the Book of Job is clearly not the motto of science that it appears to be. It is Job himself, in pain, telling his friends that neither he nor they can possibly understand the ways of Heaven and that he therefore wants to die on the spot.

Appropriately enough, Schermerhorn Hall is the site of the discovery that closed for all time the chance that death could be transcended by science. The ninth floor of Schermerhorn is now shared by the departments of biology and art history; rooms full of slides of paintings and sculptures spill into rooms full of slides of tissues and organs. In a room here in 1910, Thomas Hunt Morgan established the physical reality of a half-dozen genes, showing that a number of different genes were actually different pieces of a fly's chromosome. In this first demonstration that genes were chemicals, Morgan opened a line of research that led, in only a few decades, to our current understanding of DNA-based, chromosomal inheritance as the chemical mechanism for the inheritance of variation from generation to generation on which Darwinian natural selection depends. Speaking to the Earth after the fashion of science, these followers of Morgan have unexpectedly converged on Job's vision of the natural world. Because life is chemical in its deepest essence and random in its origins, they have shown that it need have no purpose beyond its own propagation; in studying the details of the history of life, they have found that the survival of life on this planet has always depended on, and always will depend on, the death of individual living things.

It is not merely that the death of any individual organism hardly matters. It is that

individual deaths are essential: random variations in DNA that arise in one generation can enter the competition for survival only through succeeding generations. Each individual death means the loss of a singular version of DNA, to be sure, but for a species to survive, the individual members of the species must die. Science claims to control what it can understand, yet death is one aspect of life we can understand all too well without any experiments and the one over which we will never gain an iota of control. Faced with these facts, both biology and medicine have become stuck in a long series of persistent, clever, but useless attempts to ignore them: medicine, by insisting that death is its failure, and biology, by insisting that death is not interesting.

We may know how to counter the effects of aging within a few years or a few decades or never. People dying in very old age after having been successfully kept from the slow decline of aging will still want — as we do even now — any assurance they can get that the quality of their remaining lives, however short, will be preserved until the very moment of death. In *these volumes*, we see that there are indeed physicians and scientists who consider that last task to be of scientific interest and worth the work. We see as well, many strategies for getting past giving false promises that every condition is curable in principle, that impending death is the failure of a cure, to instead concentrate on the medical and scientific aspects of the very last stage of life — that is, on dying.

Today, with the majority of people dying before eighty of infectious, environmental, behavioral, and inherited problems we cannot yet solve, this issue may seem premature. But there is a risk involved in not confronting it now: silence means we will see biomedical research continue to use each successful reduction in premature death as an excuse to avoid dealing with death's inevitability. The old people who today suffer avoidable disease, unnecessary isolation, and pain in their dying are the major victims of this avoidance of the link between aging and death. They deserve a better deal than the one they are getting from today's medical science. Not for them alone, but also for today's children who will be the aged of 2050 and beyond, science and medicine have to learn how to attend to the problems of the dying.

The medical treatment of the dying is almost invisible today, an embarrassing situation that can only get worse as the rest of medical science succeeds in allowing a greater fraction of the population to live into old age with sufficient residual mental and physical capacity to understand their situation. For the sake of these lucky people — may we all be among them — medical science is obligated now to begin a research effort focused on making dying itself as brief, and as healthy, as possible. This is no joke: the hospice movement — not a product of scientific medicine but a reaction to it — has shown that a dying accompanied by a minimum of pain and a maximum of social interaction is healthier and better by far than the typical dying of today, accompanied as it so often is by prolonged agony and isolation.

For most of my life, and for all of my thirty years as an experimental scientist, I scrupulously avoided my own personal and professional responsibility to attend to the dying. It is not that I had no chances to make the connection between science and dying; I simply chose not to take them. In my own confusion, I lost sight of the fundamental truth that dying is as distant from death as any other stage in life is.

The deaths of my parents bracketed the period in which I came to see how a failure to

acknowledge death properly distorts the practice of medical science. My father died of a respiratory infection acquired in the hospital a decade after he had lost his senses to Alzheimer's disease. During his last years I did not see him at all, and I did not understand that he was dying, for I already imagined him as dead. He lived for many years in a home for the demented, his body kept alive by strangers because his family — myself included — could not carry the burden of caring for him after he ceased to know who we — or anyone else — were. He was allowed to die at last, of pneumonia, because my parents had signed papers in advance, asking that their lives not be extended by heroic measures once they had crossed an irreversible threshold of pain or dementia.

My mother survived him, and in her last months, and even in her last days, she gave me and my family ample evidence of the difference between dying and being dead. She became stronger as she became weaker, became increasingly generous and wise with me and my relatives, and with a host of new and old friends, in ways that she could not while she was more fully alive. This stunning emergence of a kinder and wiser person from the dying body of my mother came to a halt only in her last few days, when the pain of her tumor began to require such high doses of morphine that she was unable to speak with any lucidity. Even then, she clearly accepted her death, said good-bye, and, with the help of hospice care at home, died peacefully.

Hospice care is still controversial at many major medical centers today, for its goal is not to provide curative treatment for the dying but to provide a good death. At their best, hospices excel at delivering what they promise: control over pain, dignity to the end, and the assurance that no one need spend their last moments alone.

When I wrote my essay in 1999, the hospital response of science to the dying reflected my own attitudes during those decades I worked in my lab. It went something like this: “You have had the misfortune to be born too soon to benefit from science's ever deeper comprehension of nature. That is too bad, but since we can know how everything works, certainly one day we will know how to keep a death like yours from happening. Until then, you will understand if we do not spend much time on the relatively uninteresting matter of how it is to die.” This attitude has certainly not disappeared and is in evidence in many places, especially in large research hospitals in major metropolitan areas, but *Our Changing Journey to the End* shows how these attitudes are being undermined by two primary forces: the baby boomers who demand good care of their dying parents and soon themselves, and the cost of futile interventions in a time when healthcare costs are zooming. Other chapters in these volumes suggest how change could take place and how some changes are already under way in spite of the many remaining obstacles, which are also discussed.

Today, medical scientists treat very old age, dying, and death with equally fastidious disdain, as if they were all somehow intrinsically uninteresting. If they are as frightened of death as everyone else, then their disdain for aging, death, and dying is a prophecy that keeps them from confronting their fears. A good deal of interesting science lies waiting to be done by scientists able to admit their fears of death and look beyond them to study dying on its own terms.

The questions to be asked are familiar: which parts are painful and may therefore be made better by the easing of emotional, existential and physical pain; which parts are

inherited through the genome and may therefore be made better by the manipulation of the genome or the addition or subtraction of a gene or a protein; which parts are conscious, and which are unconscious, so that we may better understand how it feels to be dying and learn how to alleviate the worst of those feelings. Those questions would form a minimal agenda for research on the dying stage of life.

Beginning with Elisabeth Kübler-Ross's 1969 classic, *On Death and Dying*, many serious studies of dying have been built around interviews with people in the last days of their lives. A doctor herself, Kübler-Ross broke many rules at her hospital by insisting that the dying be given a chance to describe their feelings directly; simply allowing the dying a voice was a major accomplishment. From their narratives, she produced an anatomy of the physical and emotional stages of dying: denial, anger, bargaining, depression, and acceptance. As she points out, all but the last of these five stages express a deeper and more fundamental denial, attitudes that allow one nevertheless to have some hope. Hope in the face of certain death may seem absurd, and perhaps it is, but nevertheless the dying showed her — and many studies since have confirmed — that a dying person often does not lose hope until just before death, and sometimes not even then.

A person's last days can be the most remarkable example of dying as an aspect of living: when the end is near, a dying person begins to pull away from the world, sleeping a lot, not seeing anyone, not interested in anyone. At best, and without pain, the end of life seems quite remarkably like the beginning, the clock of internal time run backward one last time, to the earliest days of infancy. Kübler-Ross counseled that hope should never be denied, that the dying should not be burdened with facts that would remove all hope before the person was ready to set it aside, and that the enemy of the dying is not unavoidable death so much as avoidable physical and mental pain. In the decades since Kübler-Ross's book came out, about a third of her readers have passed through her five stages and died. In all that time, precious little has been added to, or taken from, her five stage formulation of dying, and almost nothing has been done in science to carry out any of her prescriptions.

There is, then, a realistic scientific agenda for the period from the moment when there is nothing that medical science can do to stop death from coming until the moment of death. It is to understand the mind and the body well enough to keep both as free of pain, and as free of isolation, as possible. Science can complement the work of a hospice by providing it with new tools to accomplish these ends.

Much dying today happens poorly, with unnecessary pain. It is time for medicine to acknowledge what torturers have always known: pain is a pathological state that mocks any pretense to health. To uncover the underlying mechanisms of pain, it is useful first to recall that no matter what part of the body is in pain, the hurt is, of course, in the head. Pain is a brain state, and as such it ought to be as understandable, and treatable, as other unwanted brain states are turning out to be. The most effective painkillers we use today work only by dulling the senses, and all are highly addictive when taken by people whose lives are not almost at an end. Doctors who try to prescribe large enough doses of these compounds — morphine and its derivatives — are often suspected of inducing a dying patient's addictive craving.

This is a cruel joke to anyone who is dying with intractable pain and who may reasonably argue that one cannot be addicted when one is dead. A civilized medicine that

fully accepted the reality of death would also recognize that the pain itself is as damaging as any addictive state. There is another, equally ironic barrier to the straightforward study of the proper pharmacology for intractable pain: the fear that an overdose of morphine might be used intentionally to shorten the life of a dying person, with or without the person's consent. It is ironic because the most frequent reason for requesting an early death is precisely unbearable pain.

Beyond the tragedy of dying people having to hasten their death with the same compounds that might have given them a reason to live longer, the denial of proper painkillers damages a person's body. A person in pain suffers from a reduction in the efficiency of the immune system and usually cannot actively participate in any other courses of treatment. We need a major effort to find or synthesize — and then to distribute openly — a new generation of more effective painkillers. Such research would need strong government support, since the political problems of such research and development make these studies as uneconomical as vaccine production for today's pharmaceutical firms.

The “how” of mental life – the mechanisms of gene expression, protein synthesis, and cellular communication that work so well for a century in some brains but not well at all in others — are at the intersection of basic biomedical science and the right of a dying person to full membership in society until the last moment of life. It may take decades or longer to fully understand the molecular biology of mental life, but it is not too early to say with confidence that whatever the molecular mechanisms involved, people need the touch of other people's hands — those soft touches that let them know they are not alone — all their lives, to the very end. The cruelest of the paradoxical consequences of the denial of death in modern medicine is the insistence on treating a dying person in ways that destroy all chance of privacy and dignity, that deny the person the ancient right to the continued presence of friends and family.

The usual argument for leaving the dying person alone in a cold room with tubes and monitors blocking all human interaction, for allowing the rarest and sometimes the richest of words to go unheard or unsaid, is that this regimen is necessary to extend the person's life, albeit only for the shortest of times. But to extend external time by so little while removing all chance of the person's sharing any of the little internal time left with anyone else is surely another form of *de facto* torture, equal to withholding painkillers.

With this short Foreword, I welcome you to *Our Changing Journey to the End*.