If we are to come to a place where the final hours of life are to be given meaning, we must remove the stigma from them. We must take these hours back from the helplessness and powerlessness that so often surrounds them. This is a problem I see constantly in working with the dying.

This involves three areas of change. First, it means that professional and volunteer caregivers MUST model meaningful interventions near the time of death. The medical model of intervention, while certainly appropriate to the medical issues, continues to be the intervention of choice, especially since hospice care has come to utilize Medicare reimbursement.

Health care has fallen victim to the Industrial Age. Surgery and technology has become the answer to every form of malady. Indeed, we expect and anticipate that everything capable of being done on our behalf, will be done. So, we institute artificial feeding in the belief that any form of life is better than no life at all. The hilarious movie, Critical Care, lampooned this industrialized approach to health care. One physician, inside a massive computer center, monitors the vital signs of hundreds of patients all over the world. He is capable of completely treating all these patients from his monitor. As Werner, a budding resident in search of getting a peachy fellowship, stares over the physician's shoulders at the computer screen, he remarks with amazement at the ability of a single person to monitor all these lives and do all of these interventions from one single computer. The physician, without taking his eyes off the screen, replies, "There is no longer any person that we cannot keep alive. Only those we choose not to maintain."

Yet another, and more recent societal trend, is our progression into the Information Age. This is reflected in our drivenness to collect, collate, and distribute information. Everything must be preceded by a double-blind study, by standard deviations, and by graphs.

We appreciate the necessity of research. But, it seems that patient care, what really happens at the bedside, has taken a backseat to the development of needs testing, quality improvement seminars, and surveys.

Health care is equally obsessed with documentation. Some of it, of course, is related to the litigiousness of our society. But, more of it, it seems, is the belief that, in order to give better care, we need better data. And so, in our forty hour week, we stumble around trying to make sure the ever-swelling data we report conforms to the edicts of managers and statisticians, people rarely seen at the bedside.

Reality dictates that some of this is necessary. But, ask the increasing numbers of nurses who are leaving their chosen calling, Why are you quitting? In most cases, they'll tell you that they are no longer doing what nurses are supposed to be doing, caring for the patient. We spend all of our time doing documentation. We work long hours, and most of it's on charting. That's not what professional caregivers signed up for. It's not enough to have patients as the goal later on. They must be our goal now.
Personal presence takes a back seat, especially as profitability moves to the foreground. Yet, it is personal presence that promises the greatest reassurance and hope to the dying. While we must INSIST on control of symptoms, this cannot be the focus of our interventions.

Secondly, it means that we must do a better job of communicating and educating ourselves and the public on the hope that is inherent in the dying process. Indeed, hope is the correct word. The dying process is pregnant with possibilities for growth, reconciliation, and yes, even healing (of a sort). When we aggressively treat the medical issues, we clear the stage for entering into the existential concerns of the dying. These are the greatest issues of concern. When I speak with a bereaved family member, they say that hospice was great not primarily because we controlled the pain, although that was absolutely essential. It is because we made a fundamental change in what they expected the dying process to be like. We invested the dying process with imagination, presence, insight, and compassion. We gave them tools with which to handle their hopelessness and helplessness.

So, when the nurse, perceiving the patient’s anxiety, dims the glare of the fluorescent lights in the room, brings in some calming aromatherapy items, and plays some gentle music, she transforms the patient’s room from an impersonal clinic to a sanctuary of nurture and healing. She steals away the darkness and despair; she redeems the circumstances. This is our task. This is the kind of memory that lingers on the lips of families with whom we have done well.

Thirdly, it means that we must re-imagine the death process. Our belief about the dying process seems to be that it is a hopeless, and ultimately, meaningless endeavor. Nothing could be further from the truth. The Bill Moyers special in 2000, On Our Own Terms tried desperately to communicate the idea that death and dying is full of meaning and potential, when faced forthrightly and aggressively. The dying process is a time to take care of many important tasks.

During this time, we have the opportunity to reflect on the meaning of our lives. We have a chance to make amends for, and perhaps even build, powerful relationships. We are able to focus on our understanding of the meaning of our lives in light of our values. We are able to say goodbye and bless those whom we are leaving, thereby preparing them for life without us.

In Neil Chethik's marvelous book, FatherLoss: How Sons of All Ages Come to Terms with the Deaths of Their Dads, he relates the story of a conversation he had with Dr. Dennis Klass, a child psychologist at Webster University. Chethik asked Dr. Klass, how he'd recommend breaking the news to a boy whose father was dying? He responded: "Probably, Dad ought to be the one to talk to him. Then we give the Dad a chance to dump as much fathering as he can into those moments. If I were working with the dad, I would at least give him the opportunity to make a tape or write a letter. 'Here's what I would have said to you when you turned twelve. Here's what I would have said to you when you turned sixteen.'" Every time I read that I tear up. Preparing our loved ones can have an enormous impact on how they cope with our loss. It illustrates the possibilities inherent in this time of change. The dying process can be a time of unparalleled growth.

Probably, there's yet one more thing we need to take away the stigma of death. That is, to be present for a good death. The family has all gathered around. The past is addressed, if not forgiven, hands are held, and there is the sound of a final, gentle breath.