Herbert Anderson and Thomas A. Nairn, O.F.M.

Fitting Time

My father died last July. He lived for "seventy-five good years and two bad ones." The two "bad ones" were the two years he lived without his wife and my mother Stella. My mother died in a hospital two weeks after she suffered a massive stroke. Everybody, including my father, understood and agreed that she needed to be in the hospital. Tom O'Neill, her husband of forty-two years, could not have cared for her. When the doctor told us about extensive hemorrhaging to her brain, everyone in the family agreed to withhold everything but comfort measures—except my brother Jim, who was still hoping for a miracle. Seeing his wife die in the hospital gave my father new resolve about his own death: when it was "his time," he announced to us one day shortly after mother died, he wanted to be at home. "Gramps in Charge," as his grandchildren called him, had picked his place to die. Only the time was undetermined.

My father did not live easily without his wife Stella. He was lonely. He lost his appetite for living. He gave himself a year to "sort through," as he put it, all his feelings and memories about Stella. Within six months of mother's death, however, my father was diagnosed with lung cancer. He had not finished mourning his wife's death before he had to face his own. A lung was removed and radiation treatment followed. About the time my father began to regain his strength, he experienced diabetes-related medical difficulties, and finally the word that the cancer had metastasized to the brain.

All of us felt "his time" had come, but nobody spoke of it. It was the grandchildren who said first what all the adults were thinking: "How long do you think we'll have Grandpa with us?" they would ask. As the symptoms began to mount, most of the family agreed that "his time" had come, albeit much too soon. Everyone except my brother (who was still mourning his mother's death) determined to support the passage toward death rather than fight against it. Tom O'Neill walked straight into the unavoidable and the mysterious. He responded to death much as he had responded to other challenges in his life: it was something that needed to be accomplished. And he would do it his way, at home. "Pain's a lot easier to deal with in the comfort of your own home," he said. I think my father felt safe knowing we would take care of him like *his mother* took care of *his father* at home when he died of cancer.

Once we could all agree that "his time" of dying had begun, my father began to tell stories about his youth, dating, his high and low (!) adventures as a young man, his early business days, about his family, all of which connected his living with his end time. Dinners with my father took on new significance when he began telling stories. His grandchildren prompted him, and he usually complied with gracious urgency. As my sister put it, "He simply wanted to empty himself of these memories and adventures because he wanted us to know all about his life, even as he anticipated his death." My father's remembering always made him feel better. It was as if he was determined to be known fully before he died. We felt better too. Moreover, each of us got to know my father in a much deeper way than we had known him before.

The anticipation of death was not any easier for him, but Tom O'Neill provided us, his children and grandchildren, with stories to cling to and claim after his death. By the time the end finally came, we had all said goodbye. When we gathered around the lazy-boy chair for *Viaticum,* my sixteen-year-old daughter spoke for everyone: "You don't have to pray too long, Father Paul, because Gramps is pretty tired and he's been ready for a couple of days now." Hearing his stories had prepared us to send him on his way to God. It was the fitting time for Tom O'Neill to die.

Two days later, my father died peacefully in his own bed, after a day and a night of "active incoherence," as we named it. After he died, we sat around the bed and shared more stories and cried for my father and for each other. I continue to grieve peacefully and gratefully for my father: peacefully, because we were able to honor "his time" of dying; gratefully, because of each storytelling moment my father shared with us during his dying. Even my brother, who had initially withdrawn, was drawn back to his father through the stories. My father's own version of his life was amplified at the wake and funeral and the dinner that followed. Telling my own story of my father after his death has been made easier because I know his version. Had we not decided to honor "his time" of dying, however, we may not have known the stories he told that now linger in our memory of Tom O'Neill.

Melissa O'Neill Smith

The purpose of this essay is to explore the difficult and ambiguous period of time when family, patient (whenever possible), and medical staff must determine that an individual who has been critically ill is now irreversibly dying. It often begins when a physician reports to the family that "we have done all that we can" or "there is not much more we can do for your loved one." Behind those statements is the assumption that everything that could reasonably help reverse the course of an illness has been done. This is an important determination because it (a) shifts the focus regarding the patient from cure to care, (b) establishes *Viaticum* (or the Commendation of the Dying) as the appropriate ritual, and (c) creates a time in which families may be open to stories that will help the dying person bring closure to a life. It is still a difficult decision to make in our cultural context where death is the enemy and medical technology continues to promise one more remarkable procedure. The death of Tom O'Neill particularly illustrates both the importance and complexity of determining the "fitting time" to acknowledge that an individual has entered into the process of "irreversible dying."

The literature about end-of-life decisions can sometimes give the impression that such decisions are relatively straightforward. For example, the *Ethical and Religious Directives for Catholic Health Care Services* from the U.S. Catholic bishops simply states that a person has an obligation to use ordinary or proportionate means of preserving life but may forgo extraordinary or disproportional means. The distinction between the two is based upon an assessment of burdens and benefits to the patient, family or community (N.C.C.B., 22–23). Anyone who has been involved in such decisions, however, knows that they are inherently ambiguous (see Nairn, 39). Elsewhere in this issue, Zachary Hayes has noted the Church's tradition regarding the *ars moriendi,* the art of dying. Both ambiguity and art are present in Stella and Tom's deaths.

DECIDING FOR STELLA: AN AMBIGUOUS ART

When Stella awoke on her fateful morning, she had no idea that it would be her last day of consciousness. Strokes are the third leading cause of death in the United States. Of every thousand people in the United States over age seventy-five, between twenty and thirty will suffer a stroke each year. A third of all strokes are fatal (see Nuland, 64). Stella was rushed to a hospital and soon entered an intensive care unit, where physicians used all the technology available to keep her alive. Appropriately, the immediate medical response is to seek to redress the trauma or cure the illness. It is only later that families like the O'Neills must make the ambiguous decision to care but not seek for an impossible cure. Stella and her family quickly became part of the medical culture in this country, a culture with its own rituals, narratives, and with a language not always understood by untrained ears.

Since Stella did not regain consciousness after the stroke, the ambiguity inherent in end-of-life decisions was intensified. She could not participate in the decisions regarding her treatment, nor was she able to articulate her wishes, as Tom did later, regarding where she would like to die. Because the stroke came suddenly and unexpectedly, Stella had no opportunity to say her farewell to family and friends. We do not know from the story whether Stella O'Neill had previously executed a durable power of attorney or another advance health care directive. Usually, such documents are the only way to ensure that the patient's point of view regarding continuing aggressive care or the withdrawal of treatment is respected by physician and hospital. Preparing a document such as durable power of attorney may also be a time when members of a family hear a person's wishes clearly stated and understand why these choices are important in the light of their values and beliefs. A variety of guides are now available to help such preparation, including a guide consisting of twenty-five questions produced by the American Association of Retired Persons and a more complete guide produced by Aging with Dignity entitled "Five Wishes." In the absence of advance health care directives, there is no guarantee that any family member or friend may speak for an incompetent dying patient.

In the situation of Stella, the O'Neill family members were invited into the decision-making process and allowed to express their understanding of what she would have wanted. American law, however, insists that those who engage in end-of-life decisions are not to act on what they personally think is in the best interest of a dying person. Rather, the members of Stella's family needed to determine what they think she would want under the present circumstances at the present time as the basis for making a decision. Such decisions are called "transmitted decisions." The extensive hemorrhaging in the brain made the medical decision clearer than many other end-of-life decisions that families face.

THE DIFFICULTY OF DECISION-MAKING AT THE END OF LIFE

Often, family members like Jim still hold some hope for cure or more life when they must decide whether or not to try another, perhaps more radical, intervention. Despite Jim's "hoping for a miracle" for his mother, his sisters and father moved ahead with the decision to take Stella off the ventilator. Family disagreements around end-of-life decisions are not always resolved easily or peacefully. When the family conflict is particularly intense, hospitals are likely to side with those seeking more medical treatment, especially if litigation is threatened. In the absence of durable power of attorney or another advance directive, the hospital will often choose the most conservative course of action. This possibility shows the need for *one* designated agent of the patient. It also demonstrates the necessity for the designated agent and other family members to understand and respect each other.

Family members need to put aside personal differences and particular treatment preferences in order to focus on determining what the family can do to respect the dying patient's wishes. If, however, individual family members try to dominate the decision; the wishes of the patient may be ignored. Occasionally, families are afraid or unable to decide for fear of making a mistake or because there are irreconcilably divided opinions among family members. As ethicist Dennis Brodeur explains, "All people experiencing the trauma or difficulty of decision-making at the end of life want to come away knowing that they did their best, that medical treatments were used wisely and with reasonable expectations, that people were freed of as much pain and suffering as possible, and that no one was left alone to make decisions" (Brodeur, 4). The aim of end-of-life decision-making is to honor the vision of life and the values of the one who is dying, insofar as we are able. When the patient is not a participant in the decision-making process at the end of life, it is crucial that family and medical staff work together and not abuse their role in this joint moral process.

There are other participants in this decision-making process at the end of life, namely, the physician(s), medical staff, and sometimes the hospital itself represented by the administrator or other spokesperson. Again, in the story described by Melissa Smith, the physician's explanation of what was happening inside the brain of Stella made the decision easier. The physician exercised her proper role, described by Brodeur as offering "assistance in understanding the scientific aspect of a medical diagnosis or treatment plan and the importance or significance of statistical information in making decisions about whether to continue treatment" (Brodeur, 4). The physician's clarity and candor enhanced the family's decision-making process.

Physicians may also refuse to cede decision-making authority either to the patient's family or even to the patient. A number of studies suggest that it is often the physician's values and not those of the patient that are decisive in end-of-life decisions (see Orentlicher, passim). Similarly, Daniel Callahan has accused physicians of technological brinkmanship, "pushing aggressive treatment as far as it can go in the hope that it can be stopped at just the right moment if it turns out to be futile." He goes on to suggest that such brinkmanship "can both save life and ruin dying; that is the dilemma it poses" (Callahan, 192). All of us have health-care horror stories, many of which may involve the questionable use of aggressive therapies during the last part of a loved one's life.

The inability to provide genuine care for an individual at the end of life stems in part from the reluctance to acknowledge the reality that there is a time of "irreversibly dying" and that this is the "fitting time." When the patient is able to decide and communicate about his or her treatment, it is incumbent on family, medical staff, and the patient to acknowledge the shift that has already occurred from being seriously ill to irreversibly dying. A person is understood to be irreversibly dying when he or she is not likely to recover or continue living for an indefinite period of time. "If it cannot be agreed that an individual is irreversibly ill and moving toward death, confusion or denial may lead to false hopes, insistence on restorative treatment, prolonged hospitalization, the search for a life-saving cure, dependent behavior, and a deterioration of relationships between family, the patient, and medical caregivers" (Anderson and Foley, 102). Although it is a difficult decision to make, determining that an individual is irreversibly dying is necessary for care, for ritual making, and for storytelling. In short, if the reality of impending death is denied, the care of dying people is diminished.

TOM'S DECISION: HIS TIME TO DIE

Tom O'Neill was obviously affected by the manner of his wife's death. He reacted to it by determining that when it was "his time" he wanted to die at home. According to recent studies, most terminally ill patients express a desire to die at home. Nevertheless, most of these people die in a hospital or long-term care facility (Pritchard, 1244). But Tom O'Neill was "Gramps in Charge" and wanted to exert appropriate control over his personal journey to death. As medicine is practiced in the United States, exercising such agency is not a simple task. When patients enter into the culture of medicine, they are assigned the identity and role of a sick person. People who are assigned the patient role are often deprived of agency and expected to be dependent. Sociologist Arthur Frank has suggested that medicine's rituals of diagnosis and prognosis create a new moral status for a patient:

> The medical interview hails a person to be a patient whose diagnosis carries the responsibility to engage in a treatment. Diagnosis does the work of interpellation: the disease becomes not only what one *has* but more significantly what one *is,* for example, a cancer patient. Medicine hardly creates the cancer, but it does create the career of a cancer patient . . . implying what a person is entitled to ask from society, and what society expects from the person (Frank, 34).

Deciding where one wants to die, as Tom O'Neill did, does not, however, guarantee that the time of irreversibly dying will be used constructively to write our autobiography, mend fences, heal broken relationships, give gifts, and otherwise bring closure to a life. For that to happen, everyone involved must acknowledge that someone who has been seriously or even chronically ill is now irreversibly dying. Tom's determination to die at home and his willingness to tell his story meant that he wanted others to know he was more than his illness. And he remained an agent in his living until he died. By means of his dying at home and by telling his story to his family (and to others who would hear him), Tom made his time of dying a "fitting time." How he died was his final gift to his family. It could not have happened, however, without the willing support of both family and physicians.

Tom O'Neill's medical situation allowed him to "be in charge." Even if his wife Stella could have died at home, it would not have been the same. He was capable of agency and therefore able to express to his family his own desires. And, more importantly, his illness was of such a nature that his family could honor Tom's wishes. Because Tom could decide and the family and medical staff concurred, no extraordinary measures were considered. If Tom had reached a point when it was no longer possible for his family to care for him, home hospice care might have been a necessary step offering the family supplemental medical and spiritual care. Behind the fierce desire to die at home one might see an equally strong fear of being abandoned to die alone. If it had become impossible for Tom to die at home, hospice could have offered a home-like atmosphere with pain control and support for living until he died. When families are faced with more difficult decisions at the end of life because of lingering suffering and/or severe incapacity, pastoral ministers and communities of faith are resources for "decisions of conscience" that must be made by those close to an irreversibly dying patient.

DETERMINING THE FITTING TIME: A DIFFICULT MORAL CHOICE

Deciding that someone we love who has been seriously ill is now irreversibly dying is a complex moral decision-making moment. It is always possible to insist that there is something more we can do, another specialist we might consult, another treatment we might try. In most families, there is someone like Melissa's brother who insists that "miracles are still possible." At the same time, the end-of-life is not simply a problem to be solved. There is also the sense that both the moment and process of dying are shrouded in mystery. "Irreversibly dying" is not an absolute category. Therefore the decision making process is an art form and the decision will be ambiguous at best. Furthermore, the process is fraught with unexpectedly powerful emotions. Melissa's brother withdrew from his father when Tom was first diagnosed because Jim was still mourning his mother's death. He had overloaded on signs of human vulnerability and needed to withdraw temporarily from the family process. A family does not usually act under crisis differently from the way they have acted before. When a family and medical staff honors an individual who is irreversibly dying, accompanies and does not abandon, and respects the patient's deepest desires and wishes, then artful dying is possible. If, however, a family or a dying individual has lived falsely, then this decision will be complicated or even impeded.

The shift from aggressive therapies to palliative forms of care, from sacrament of the sick to *Viaticum,* from being ill to dying is theologically complex as well as emotionally challenging. How we understand death will shape our response to this moral and spiritual transition. Death is part of life to be embraced with respect and dignity and not simply an enemy of life to be resisted and rejected. Death is like a thief in the night but it is also a human act. Karl Rahner articulates his paradoxical view of death in this way: "This simultaneity of fulfillment and emptiness, of actively achieved and passively suffered end, of full self-possession and of being completely dispossessed of self, may, for the moment, be taken as a correct description of the phenomenon we call death" (Rahner, 1961: 40). Respecting this paradoxical mystery of death is a prelude to acknowledging that someone we love is entering into a time of actively dying.

It is desirable that *Viaticum* not be delayed so that dying persons may be nourished by it while in full possession of their faculties. For some people, the ritual for dying may be *the* moment when everyone is able to acknowledge the inevitability of death for a loved person. Used in this way, the ritual may inaugurate storytelling as a way of marking the journey to death. In that sense, the ritual of *Viaticum* provides a framework that adds dignity to the dying process. By the time Tom O'Neill received *Viaticum,* however, he had entered fully into the dying process and had invited his family to walk with him as he told the story of his life. *Viaticum* was the culmination of narrative reflection that had included remembering his first Communion and confirmation. The renewal of faith into which one has been baptized is not only an important reminder of God's gracious promise; it is a foretaste of the reunion with loved ones who are already heirs of the promise of eternal life. Whether *Viaticum* initiates or culminates the narrative process, it is important to keep ritual and story closely linked in order to deepen the connection between God's narrative and ours. Because dying is an emotionally charged and socially complex process, it evokes the natural human tendency to cope through ritualization.

Our care for the irreversibly dying is, however, still care for people who are still living. The problems of the dying are the problems of the living. Loss of control, suffering, becoming dependent, and waiting are characteristics of living as well as dying. Because the dying have as many pathways and styles as the living, it is important that caregivers attend to the particularity of each situation. Even so, there are stories and rituals to aid the process that may also serve to enhance the process of telling the narrative of a life. The caregivers of the dying have a double task: to help someone live as fully as possible until death while at the same time mourning the loss that is an inevitable part of dying.

Acknowledging the reality that someone we love is now dying irreversibly presumes a willingness to share their grief. Dying persons grieve all the time. They are letting go of everything they have loved in order to get ready to die. Letting go of what might have been or should have been as well as what has been evokes a sense of loss and grief. In the process of bringing closure to a life, the dying person also needs to say many good-byes. Freedom to ritualize the litany of "lasts" provides a structural framework that keeps dying persons connected to those who wait with them until they die. For the dying, the grieving seldom ends with one outpouring. The dying person will need freedom to return again and again with tears to the deep sadness and grief that is a constant companion. If one can mourn the losses that are part of dying, it is easier to be with family and friends.

It is important to reaffirm the significance of good—value-laden—decision-making when patients and their families are confronted with a diagnosis of life-threatening illness and need to decide about continuing or stopping life-sustaining treatment. Value-laden decisions will include the values of the patient, family, professional caregivers, and institutions. By design, these decisions will be messy and garner a great deal of ambiguity and often emotional distress. Nonetheless, the fundamental aim in these difficult cases is to make decisions that reflect the values of multiple parties, especially the person who is dying. Sound, ethically sensitive decision-making is the goal of this process, regardless of the presence or absence of an advance directive (Brodeur, 4). Because even our best decisions are fragile and finite, however, we need to remember that all our decisions about living and dying are sustained by a gracious God.

THE MORAL OBLIGATION TO LISTEN

We began this essay with the story of a family that found a way to encourage grandfather to tell stories of his life as preparation to die. Night after night, with the family around him, Tom O'Neill told his grandchildren stories by which he emptied himself of memories and fashioned a narrative through which he will be remembered. Stories told by the dying are privileged acts of self-interpretation. Telling our story is not only a gift to those we love. It is narrating the way we want to be remembered. It is also an intentional act of agency. Even when physical constraints restrict mobility or freedom, when medical procedures may isolate us from community, or when family members are tempted to close our story prematurely, we can still fashion a life narrative (Anderson and Foley, 98ff). On the third Tuesday of Mitch Albom's *Tuesdays with Morrie,* Morrie Schwartz hooked his glasses off his nose, wagged a finger at his former student, and said softly: "Mitch, you don't understand. I *want* to tell you about my life. I want to tell you before I can't tell you anymore." His voice then dropped to a whisper and he continued. "I *want* someone to hear my story. Will you?" (Albom, 1997, 63)

Morrie's plea to his former student introduces another moral dimension often overlooked in the complexity and ambiguity of the dying process. Reminiscing and storytelling may take some encouragement. Sometimes, the dying person wishes a commitment: "If I tell my story, will you listen?" Tom O'Neill had an eager audience around the dinner table that sustained him in telling the story of his life. Family and friends and caregivers of the dying need to be ready to hear before we invite the dying to tell their story. It is our moral obligation to listen carefully to the dying person's story and respond in a way that lets them know that they have been heard and understood and will be remembered. When stories are told and heard, a bond of mutuality is created with a dying person that transforms the dread of abandonment and the terrors of isolation into a community of hope.

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"Death may be the greatest of all human blessings."
—Socrates

"Death is sometimes a punishment, sometimes a gift;
to many it has come as a favor."
—Seneca

"Lord, let your servant now die in peace,
for you kept your promise.
With my own eyes I see the salvation
you prepared for all peoples:
a light of revelation for the Gentiles
and glory to your people Israel."
—Luke 2:29-32