

## IN PRAISE OF A GRACEFUL WOMAN: MARIA HARRIS

By Gabriel Moran

This essay is a witness to the life of Maria Harris, focused on the last four years of her life, her death, and the immediate aftermath of her death. I was with her during almost every hour of the four years of her illness and at the moment of her death on February 1, 2005. Immediately following her death many people asked me if I was going to write about her illness and death. I said that I did not think so. However, after nine months of reflection, I have decided to write this memoir. I do so while still having some misgivings. My ambivalence has taken the form of the following debate.

### Should this Document Exist: Con

There are two reasons why I have thought that this essay should not be written, one pertaining to her, one to me. On her side, people have a right to privacy even after they have died. When they have suffered from a long, debilitating sickness, there are details of their life which in written form should not go beyond a hospital chart or a psychiatrist's notes. If someone wants to share intimate details of their own life with a reading public, that is their right. But it can be exploitative if someone whom they trusted publishes such details.

For myself, I am ambivalent about writing this essay because I am unskilled at this literary genre. I seldom read personal memoirs because I so often find them either boring or sensationalistic. The decision to write about these traumatic years may seem to imply that I have come to some new or profound insight about the experience. The truth is it was mostly confusion from which I cannot claim to have attained any shred of wisdom that requires being shared with the public. Anything I know about illness and death has already been said better by others.

### Should this Document Exist: Pro

Whatever my personal misgivings, this narrative is about her not me. Maria had an amazingly wide circle of friends who would appreciate knowing more about the end of her life. I have told some of them some of this story but it seems appropriate to put the whole story in writing for all of her friends. I am not trying to publish a work of literary or academic worth, aimed at the general public. This is an extended letter to Maria's friends, people who I hope will appreciate the spirit in which it is written. The material here is neither embarrassing nor secret. Obviously, there are details of a person's sickness that do not need to be in print. But as a whole, the story of how Maria dealt with her sickness and dying has a beauty to it that should be acknowledged. She approached death as she had lived her life with courage, candor, and a gentle sense of humor.

On my side, I will simply recount the facts as I remember them without worrying about literary style. I should admit that I am writing this partly for myself, to put on paper the memories that flood my mind. This seems to be the right time to do it when the memories are still fresh but with some distance from the moment of death. After a year, one's memory functions differently; the remembrances do not disappear but it becomes harder to locate the details properly.

Joan Didion's best seller, The Year of Magical Thinking, helped to tip the balance for me. Didion describes the death of her husband, John Gregory Dunne on Dec. 30, 2003, and the year that followed. She is a brilliant writer who creates a coherent whole out of numerous precise details and a roaming memory. I identified with many of the details in the book. I am not the skilled writer that she is, but I nonetheless got the feeling that I could do something similar on a smaller scale, that is, lay out the facts in one's memory and do so with a spare style that does not strive for literary effect.

In what follows, I have relied solely on my memory. There are probably errors of fact, especially in citing dates. Perhaps later I will check some sources and make corrections. There is a scarcity of personal names, sometimes because of a conscious choice to protect the privacy of people. But sometimes it is due to my inability to recall many names. The absence of the names of dozens of people who were extraordinarily helpful does not signal a lack of gratitude on my part.

Nearly all the story takes place either in Montauk, Long Island, or in New York City. In Montauk, a tiny fishing and retirement village at the tip of the island,

Maria with her usual outgoingness had developed a group of women friends in the town. They were anxious to do anything they could to help during Maria's illness. However, for medical reasons it was preferable to spend most of the time in New York's Greenwich Village where we lived in an apartment owned by New York University. People outside of New York can find it difficult to believe when I say that during this time we were overwhelmed with kindness and compassion. From physicians and social workers to cab drivers and subway riders, people were unfailingly kind and helpful. Some of that reaction was undoubtedly due to Maria's personality which seemed to bring out the best in people. Illness dimmed that light but only death extinguished the sparkle of her personality.

A single moment in Good Samaritan hospital toward the end of her life captures a central characteristic of her life. She was no longer able to do anything for herself and could not carry on a conversation. I would turn on music to which she did not react but which I felt sure she liked. I would sit in silence next to the bed, not knowing what else to do. On this day I decided at noon time to go downstairs and get some lunch. I did not know if she would understand my words, but I always spoke on the assumption that she could comprehend. I told her that I was leaving to go downstairs but I would be back very shortly. She looked up at me and said clear as a bell: Is there anything I can do for you? I almost fell over because at that point she could hardly get a word out. As far as I can recall, that was the last complete statement she made. Friends who heard the story agreed that it was a fitting sentiment as a last expression. The essential kindness and goodness of her person shone through until the end, despite the ravages of a terrible disease.

### Backdrop

A few details of Maria's life will be helpful to understanding the last years of illness. Maria had studied music and taught in elementary schools. As a member of the Sisters of Saint Joseph of Brentwood, Long Island, she had studied for sixteen summers to earn her B.A. After that, her academic career moved quickly. After getting a master's degree at Manhattan College in 1967, she went straight through for her doctorate at Teachers College, Columbia University, in 1972. While studying for her degree she began work in the diocesan office of Rockville Center. She did superb work with the emerging group of people known as parish directors of religious education. In fact, her DRE Book helped to establish the field and give a name to the role. Very quickly she was in demand across the

country and for the rest of her life she was held in high regard by educators in Catholic parishes.

Her next move broadened the base of those who looked to her for support. In 1975 she became a professor at Andover Newton Theological School, a seminary outside of Boston. I was skeptical, wanting to know how an Irish Catholic girl from Brooklyn could possibly fit in with New England Baptists and Congregationalists. To my surprise – though I should have known better – she immediately became good friends with faculty members and one of the most popular teachers in the school.

After a few years she was appointed to the Howard Chair of Religious Education. At her installation, I was one of several speakers (representing the Catholic church). I reflected on the fact that Maria was the first Roman Catholic faculty member of the school. And it was a school founded in 1807 "to counteract the influence of unitarians, atheists and papists." I said that perhaps the founders were rolling over in their graves, but I suspected that they would recognize that her presence brought to the school only vitality, intelligence and a profound religious sensibility. That this indeed proved to be the case is evidenced by numerous written testimonies from faculty and former students and the school's web site in 2005.

Maria left the place where she was respected and loved only because she missed being in New York. She thought that she would like to teach for a semester each year and freelance for the other semester. By this time, she was in demand as much from Protestant audiences as Catholic and she liked traveling to places around the United States and beyond. Not knowing if such an arrangement was a realistic possibility, she consulted with Vincent Novak who headed the Fordham program where she had taught as an adjunct before going to Andover Newton. When Father Novak heard what she was looking for, his response was: Why not come to Fordham and do that. She was surprised at being able to arrange the deal so easily, but Fordham knew that the luck was on their side.

Maria taught at Fordham for a semester a year until she decided to be self-employed in the mid 90's. She had more than enough to keep her busy. I did not fully appreciate how hard she worked until I went through her papers after she died. Most people who are regularly invited to speak on a few themes have a stock

speech to which they give some local coloring. But what I found in Maria's materials is that she prepared each weekend workshop in meticulous detail, both the content of what she would say and how she would present it. She was a very engaging speaker from a lecture platform, and she was even better in a classroom with a small group of students.

Maria always thought of herself as a writer by accident. She never set out to be an author of books. Her first books simply came along with her teaching. I think the book Fashion Me a People in 1989 was a breakthrough for her in her self-image as an author. Craig Dykstra gave her a lot of help in preparing that text and she got a better sense of what an author is. That book is still selling well, being used as a curriculum guide in Protestant seminaries and Catholic programs of religious education.

It nonetheless happened that when a literary agent pushed her to write a book on women and spirituality, she dashed off an outline for the purpose of getting rid of the agent. The agent went to Bantam Press and got a huge advance based on the outline. Writing Dance of the Spirit was perhaps the most difficult writing project she ever undertook. The result was a beautiful work that fully satisfied the Bantam editors and the book sold well. That experience led to a second book with Bantam. When Maria first proposed a book on older women and spirituality, Bantam was skeptical, but she eventually persuaded them. This time Maria negotiated her own contract. After writing the book Jubilee Time for Bantam, she had some additional material that she thought might be made into a book for a church readership. She quickly put together a small volume, Proclaim Jubilee!

This book took note of the coming year of 2000 which was about five years in the future. The year 2000 was a jubilee year in which debts are to be forgiven. For the years up to the new millennium she became a strong voice in the movement to forgive the debts of poor nations that were burdened with impossible interest payments. The New York newspaper, Newsday, did a Sunday feature on Maria's work in this area. She was invited to numerous parishes to speak on what individuals and parishes could do for the jubilee year. A few parishes bought copies of the book for each of its parishioners.

She had two other themes that especially interested her and drew invitations. She was invited to speak to many women's groups and to wrestle with the issues of the

feminist movement. She was especially interested in the development of young girls and often spoke to women faculty of high schools and colleges. A further issue dear to her heart was Jewish-Christian relations. She often worked with the Facing History curriculum that deals with twentieth-century genocide. She became deeply committed to the appreciation of the Jewish people and their history. We once were attending a program of Jewish music in a German church. On noticing that Maria was weeping, a Dutch colleague asked me if Maria was Jewish. She had strong emotional reactions to works of art and music.

Maria's father had died when she was eight years old, a traumatic experience that affected her deeply. Her mother, Mary Harris, taught in the New York City school system to support Maria and her brother Tom. The family was a close-knit unit. Maria got much of her winning personality and energetic drive from her mother. Mary Harris died in 1991 at the age of 93. She suffered from dementia in the last few years of her life (most people over 85 years old have some degree of dementia). She was in a nursing home for about five years. I can picture Maria singing to her mother amid the cacophony in the nursing home. Her mother was seemingly at peace but not conscious of what was going on around her. But the sound of Maria's singing would light up her face.

Maria's brother Tom was a gentle and kind man. Maria thought the world of him, and they remained close throughout their lives. Tom had been head of the pressman's union at the New York Times and patiently dealt with the seemingly endless difficulties that his wife had. He had just retired at age 67 to take up some serious golf when he was struck down with dementia. One Sunday morning on returning from church he could not put the car in the garage. His decline was precipitous from that moment. It involved violent behavior, something utterly out of character for him but a phenomenon not uncommon among men with dementia.

He had to be moved four times because the hospital or nursing home could not handle his behavior. I remember one particularly harrowing experience when visiting him at Pilgrim State hospital. I had the impression that each place that he went tried new drugs on him to control his behavior but the drugs quickly made things worse. When I went over his autopsy with a psychologist, I said that although it lists three causes of death I think what killed him was the drugs. She said, "I think you are probably right." The end at least was peaceful. I have a vivid memory of our visiting him in an ICU of the hospital where he died. A local

priest known to both of us happened to be there at the same time. He said the Eucharist for the three of us at Tom's bed side. It was a religious moment that Maria always cherished. After Tom's death, Maria would say: "I don't want people saying he is better off dead. That may be true but just don't say that to me now." She mourned deeply this last member of her immediate family.

She was also concerned that Tom had died of dementia and the disease appears to be at least partially genetic. Maria read that if a sibling dies of dementia, one's chances of having the disease increase by fifty percent. Maria was brilliant – except at math. I had to assure her that the statistic did not mean that she had a one in two chances of having the disease. I said that if five percent of people have dementia, then a fifty percent increase would mean that seven and a half percent of the population would get it. Her chances went from one in twenty to about one in fourteen. (I wasn't sure that the statistics meant that, but I was sure her anxiety was exaggerated). The more important thing, I argued, was that she was a most unlikely candidate for the disease. It would not hit an active, healthy, intelligently creative person. I was dead wrong.

Maria and I met in 1966 at Manhattan College. I said in her eulogy that within five minutes of our first meeting we both knew that our lives would be entwined forever. That proved to be true despite some rocky moments in the early years (nearly all that my fault). Our first book was written in 1967 and caused some stir. We wrote together when opportunities presented themselves. We also team taught when we could. Our first attempts at team teaching were fairly disastrous. We each hit the students with all that we had. Eventually we learned to adjust to the rhythm of the other; our styles became complementary rather than additive. At first I had more invitations, and she came along as the junior partner. Rather quickly, she became the famous person, and she would bring me along as part of the package. I learned a lot about teaching from her and still use some of her techniques in my classes. She was also the editor for everything that I wrote. She was excellent at editing and was inevitably right when she gently criticized my harsh tone or vague abstractions.

We were professional colleagues as well as loving partners. She used to tell people that we would spend two hours talking at breakfast. And then in the evening we would have the same conversation and get paid for it. That wasn't exactly how it worked but our last book, Reshaping Religious Education, actually did get written

that way. In 1998 on the way back from teaching in Australia I suggested we simply write down the table talk we had been having about our teaching.

In April of 2005 I was interviewed for an oral history of the 1960s catechetical movement. They wanted me to talk about Maria's part as well as my own. Maria's main influence came later, mine was largely confined to the 1960's. I said in the interview that my voice in Catholic church reform was effectively silenced by 1973 just as her voice began to be heard. I did feel that the things I cared about were not out of the picture. Maria and I collaborated on everything so that indirectly I still had some voice. She could say things in a way that did not alienate people. Even when she advocated fairly radical things, her opponents found it difficult to dislike her. Except when bans against me occasionally spilled over to her, she was always and everywhere in demand. In the 1970s she could playfully introduce herself as a priest of the diocese of Boston; no one missed the serious point she was making with a touch of humor.

She could charm most men right out of their socks. This included a fair number of bishops with whom she disagreed but who never banned her appearance in their dioceses. In her eulogy I told the story of one of the most conservative Cardinals in the U.S. church who took a shine to her. I don't think he had a clue as to what she was talking about. He called her aside and told her she could call him AFather John.≡ She received friendly notes afterward. I would often ask her what she and Father John were up to.

I think she was at her best in giving encouragement to young women that she met during her travels. She had a talent for spotting bright young women who were on the shy side and just needed a little encouraging to let their light shine. She did not make a project of such people; it just seemed to happen. She would become friends quickly and deeply. To this day it puzzles me how she did it. Strong bonds of friendship take time to develop and require continual cultivation. I cannot figure out how she had enough time to sustain so many lasting friendships. When she was with anyone, she conveyed a sense that he or she was the most important person in her life; and for the present they were. At the funeral, several people said to me jokingly: "And I thought I was her best friend." I have a list of women in many U.S. states and several foreign countries who were her best friend.



The fifteen years before her illness was an idyllic time for us. We were about as happy as human beings can be. We were both doing what we loved to do and what we believed was important work. We traveled to many parts of the world and met wonderful people. When home we had the best of city life and our small piece of paradise at the ocean. I picture Maria sitting in the hot tub in Montauk on a cool Fall evening. She has a glass of wine in her hand and is saying: “How could a couple of people like us possibly be so lucky?”

### Ominous Signs (Summer 2000 to Summer 2001)

If dementia is in fact genetic in origin, then no doubt there are telltale signs before its onset. Usually, the signs are not obvious except in retrospect. The most extensive research project on dementia is being done on a congregation of six hundred nuns who have agreed to submit to annual tests and to have autopsies. One surprising finding has been that it was possible to identify from handwriting in the novitiate which woman would later have dementia. Certainly, early onset of Alzheimer’s (people in their 40s and 50s) runs in families and is especially devastating.

I think Maria began to have problems in the middle of the year 2000 but at the time I thought any problem was minor and passing. Maria was amazingly free of health problems. I used to fill out for her those omnipresent forms on clip boards that every physician’s office gives you. The form asks you for a complete medical history. I don’t think they believed me when I would turn in the form with nothing checked. She had suffered no serious illnesses or surgery, except for carpal tunnel syndrome acquired from typing at the computer.

The first noticeable problem came on a trip to Israel in July 2000. We were going to a meeting of an organization called ISREV (International Seminar on Religious Education and Values). Both of us had been members since 1980. Among the hundred or so members from up to thirty countries, Maria was a bright light, livening up both the academic and social aspects of the meeting. Maria leading the group in singing on the last night of the conference was always a high point.

We had made our tickets through London because we planned to stop in London for a few days on our return. London was one of the places Maria most loved and we usually managed to get there once a year and spend a lot of time in museums. I

knew the Tate Gallery better than any New York museum. The trip started badly; British Airways had problems with two toilets on the plane which delayed the flight four hours. We knew as we took off from Newark that we had missed the connecting flight to Tel Aviv. British Airways did have the decency to put us up in the Heathrow Hilton for a day and we watched the last day of the British Open as Tiger Woods wiped out the field.

I also spent that Sunday afternoon frantically trying to get through to the meeting=s organizers in Jerusalem. Both Maria and I had duties on the first day of the conference and I had to inform them we were not going to be there. We finally did get there embarrassed to be twenty-four hours late. Maria seemed tired which was natural enough, but it turned out she had an infection that required medical attention. At the time it just seemed a bother; she had developed a similar problem on the fifteen-hour flight from Seoul a few years earlier. Maria was fascinated by the medical care she received from a Palestinian physician. Still, she was subdued for the whole conference. It proved to be the last conference she was able to attend.

When we got back to New York, she began talking about retirement. As I noted earlier, the year 2000 was her busiest time ever with invitations to speak on jubilee. I encouraged her to cut back on work, that we did not need the money, that she was really free to do whatever she felt like doing. I did not think she would be happy if she just stopped. I tried to think along with her how she might take work close to home that did not require a plane ride and a motel stay. She did retreat work in two places that are an easy drive from Montauk. And there were plenty of places within a convenient train ride from New York. She had commitments until the end of the year, but she stopped taking invitations beyond that.

She had some uneasy moments at presentations that Fall but I still thought it was just overwork that needed only rest. But she had an experience in Erie, Pennsylvania, in the late Fall that shocked her. She was doing a weekend workshop and on the Saturday afternoon her mind went completely blank. She was terribly embarrassed at having to cancel the remainder of the program, even though her hosts were only concerned for her health. This incident was indeed worrisome, but one could still hope that the problem was a passing blip. For her that was the end of what she had been doing so well for twenty-five years. She feared having a repeat of the forgetting.

I tried to coax her into taking on a non-threatening situation. I said that the women at Cor Maria retreat center in Sag Harbor where she had a remaining commitment would understand if a problem developed. The director, Ann Marino, was a close friend and many of the women who attended were friends from Montauk. I quoted Rilke: "If tigers come into the temple, make that part of the ritual." But a shift of personality had begun. She had always been self-confident, assertive, and direct. Talking in public had never been fear inducing. Over the next few years, we had to have a near reversal of personalities. I had to take the lead in situations where she had always covered for my social ineptitude. She became dependent in ways that she had always avoided.

In the months that followed she became very jumpy. She used to refer to having the heeby-jeebys. Her primary care physician, who was a heart specialist, could not find anything wrong. She sent Maria to a psychiatrist. His first approach was to get Maria to draw on spiritual resources. He was taken by her background and personality. When meditation did not work he switched to medication. He tried a series of drugs, each of which produced a bad reaction. I think each of them was an anti-depressant, but depression was not her problem. On one occasion in the Spring of 2001, I was in New York for my teaching duties and she was in Montauk. I got a frantic phone call at 4 AM. She was almost incoherent but said that she was calling the ambulance service to take her to Southampton Hospital. I did not know what to do. But she called back at 7 AM to say she was better. When the volunteer EMS team arrived, she was embarrassed to tell them it was a false alarm. They assured her it was not a problem for them; they were glad for her that the ambulance was not needed.

The main problem at this point seemed to be the psychiatrist whose trial and error approach to drugs was not working. She left him but we did not have a ready replacement. We were hoping that with rest and without drugs she would regain her zip (her hairdresser in East Hampton insisted that was the remedy and Maria seemed to believe in her hairdresser's wisdom). When we visited my family in April, they noticed that Maria seemed tired and somewhat withdrawn, not the way she usually was at family gatherings. In April she also came to my class on Twentieth Century Philosophy. She was always a burst of energy when she came to my classes as a guest speaker. On this occasion she gave it her best, but it was the first time ever that she did not make a strong impression.

In July 2001, I went to teach in Brisbane, Australia. We had previously taught at the Catholic University of Australia and they had invited us back. They were more interested in her, but I offered to do it alone and they agreed. As the time approached, I did not want to break the long-standing commitment. But I should not have gone because I was a physical wreck. I had been suffering all year from undiagnosed lime disease. In March, the lime disease brought on tinnitus (loud noise in the head that made hearing difficult) and led to unnecessary knee surgery in May. The lime disease was finally diagnosed the week when I was to travel but that meant starting on a regimen of strong anti-biotics.

Because I did not want to leave Maria alone for a long period, I went to Brisbane and returned within a week, teaching a thirty-hour graduate course while I was there. I can still picture Maria as I was leaving her at JFK; she looked confused and frightened. She who had been breezing through airports every week for many years was concerned about finding her way out to the street. I repeatedly explained where to go to get a taxi that would take her home. I called each night from the motel in Brisbane where I stayed. We talked at great length (the motel keeper thought there must have been a mistake on the phone bill until I told him that I had in fact made those calls). She seemed calm but very lonely.

For her birthday in August, I gave her what would seem to an outsider a strange gift. I told her that I would renew my driver's license (after a 45-year hiatus). I would then be able to take over some of the driving if she wished me to do so. I was not sure how she would take the offer. Giving up the car keys is often one of the most difficult steps for someone in an early stage of dementia. Maria liked to drive. It was for her, as for many people, a chief sign of her independence. Since I have had a lifelong hatred of the automobile, I was happy to reverse the usual roles in which the man is assumed to be number one driver.

I was relieved that Maria accepted my offer enthusiastically. She did not sense any plot to take away her keys nor at that moment did I have any plan to do that. But I sensed that it might become necessary in the near future, so I had better start preparing the way. She did not seem to be having problems and she continued to do some of the driving. At the end there might have been some danger but fortunately she never had an accident. The last time I remember her driving was at the end of November when I had to go into Southampton Hospital for my lime

disease. I was still uneasy driving through the Hamptons, and I asked her to drive part of the way. She never lost her confidence driving but she later enjoyed being in the passenger seat.

In August, Maria's friend, Rosemary Crumlin from Melbourne, visited with us in Montauk. Rosemary always seemed to find a way to go through New York on the way to anywhere else. Maria had a great fondness for Rosemary. They had met in 1985 when Maria spent six weeks teaching at the National Pastoral Institute in Melbourne, where Rosemary was the director. Through phone calls and periodic visits they managed to keep in touch. I often said you know someone is a good friend if she travels 12,000 miles to visit you.

Rosemary was struck by Maria's change of appearance from the previous year. She was concerned about several things Maria was doing, including driving. On two evenings, Maria had what later I came to call hallucinations. When we were sitting and talking in our apartment, Maria began to see a different person than Rosemary. Later, she dismissed the moment as a curious mistake. But on another evening she had a kind of vision. Rosemary awoke to find Maria standing over her and asking: "Are you an angel?" That was a more shocking experience, not unpleasant but definitely not a run of the mill experience.

Rosemary is an unusually insightful, honest, and direct person. She took me aside and asked: "Has Maria been diagnosed yet?" I was taken aback by the question because I was still denying what was becoming obvious. I reluctantly had to admit that Rosemary was seeing the situation more clearly than I was. I appreciated her candor and concern.

The incident that pushed my thinking over the edge happened in New Hampshire later that month. We were visiting with my three sisters and my brother. Maria had the greatest affection for my siblings (and they, her). She had only her brother for family and now he was gone. My family had become her family. On Saturday evening the family sat around the dinner table, talking for hours as is our wont. Maria, however, was not in the conversation at all. I finally excused us and went upstairs to the bedroom with her.

While we were getting ready for bed she suddenly asked: "Who was the woman in the red dress?" I was flabbergasted by the question. Maria had known my sister

Louise for almost forty years. She then proceeded to ask about each of the people at the table, every one of whom she had known well for years. At that moment what crossed my mind was the thought: At some time in the future she is probably going to ask me: “And who are you?” I was right. The “some time in the future” was exactly a year later.

#### Diagnosis (Oct. 2001 to Nov. 2001)

At the end of the summer of 2001, it was apparent that Maria needed help but I did not know where to turn. Then, completely out of the blue, Maria received a phone call from a psychiatrist she had seen in Boston more than twenty years ago. She had not seen her since then, but Maria tended to leave a strong impression on the people she met. Apparently without any instigation, this woman called and asked Maria how she was. Perhaps sensing a problem from something conveyed in the conversation, the woman said that if Maria ever wanted to talk to a psychiatrist she had a friend she could recommend. This psychiatrist was in the East 70s, an easy trip from where we lived on 8th street.

Maria took up the suggestion and made an appointment. But getting there turned out to be a problem. Maria was suddenly fearful and confused about using the subway. It was a simple trip as I explained over and over. She still managed to get lost on the train and confused about getting into the woman’s building. The woman was very kind and much impressed by Maria; nonetheless, she did not seem to know where to begin. By the third visit it was clear that I would have to accompany her. And anyway the psychiatrist wanted to talk to us together. Maria did not see much point in what was going on and frankly I was frustrated, too. However, in early October the psychiatrist called me and said she was concerned that Maria had physical and mental problems which she could not treat. What she did was to get us an immediate appointment at the Neurological Institute of Columbia Presbyterian Hospital.

After meeting with a neurologist at the hospital we went back for a whole day of testing. Maria was exhausted by a battery of psychological tests that lasted about five hours. What little skill she had in math was now gone so the test was endlessly frustrating. After that day she went for various physical tests, including an MRI of the brain. Finally, after a wait of six weeks we were given an

appointment to get the results. We met with the neurologist that we had initially seen.

Both Maria and I expressed our fear of Alzheimer's. The neurologist provided a relief by first saying that it was not Alzheimer's. She said she was fairly certain of what was the matter but one symptom was missing. She asked Maria if she had ever hallucinated. Maria told her about mistaking Rosemary for an angel. The neurologist said that confirms the diagnosis. "You have Lewy Bodies," she said. I asked how to spell the word. I did not think I had ever encountered the term. Actually, I had seen it before on the autopsy report of Tom Harris, Maria's brother. At that time it had not registered in my memory. My second question was: "What is it?" Her response was: "Do you have a computer?" When I said I did, she said: "Look it up on the Internet." To put it mildly, I was surprised by her reply. I said: "Don't you have a pamphlet or something you can tell me?" She said no, she did not. She wrote a prescription for the drug called Aricept and told us to come back in six months. When we protested that was too long, she said to come back in three months.

I left the meeting puzzled but with a ray of hope. We had a name for the disease and a possible treatment. I was unacquainted with Aricept, the standard drug for Alzheimer's. Maria was familiar with it, so she knew more than I did about what the prescription meant. Maria's concern was that she had read that Aricept is only effective for six months. That is not true but the effectiveness of Aricept is still a debatable issue.

When we got home I immediately went to the computer. When I called up the literature on Dementia with Lewy Bodies, the first sentence I read was: "This disease is progressive, completely destructive and always fatal." The news did not get any better after that. I looked in vain for any glimmer of hope. The description of the disease said that people live with it for an average of seven years. Averages in such a case tell you nothing about an individual. One person might live one year, another person ten or twenty years. With Maria's health record she was not in imminent risk of death. But living for years or decades with a destroyed mind was truly dreadful. I am sure there are worse things in the world but at that moment I could not think of anything worse than watching the person you love slowly losing her mind.

I was furious at the neurologist, much of it displaced anger. First thing Monday morning I called, hoping to learn something – anything that would be helpful and positive. I was told that she returned phone calls only between 3 and 5 PM on Fridays. That added to my ire but I said I would be sitting by the phone from 3 to 5 on Friday. Come Friday I waited until it was after 5PM. When I called her office, I was told that she had been busy. I concluded that she did not want to talk to me. At that point I didn't want to talk to her, either. I was disgusted at her handling of the situation. On reflection I guessed that she did not want to discuss the horror of the disease in front of Maria. But she could have taken me aside and said something human to human. She is supposedly a brilliant researcher but her interpersonal skills left room for improvement.

We went back in three months and received an additional drug. Maria was subjected to more long mental tests. She resisted doing the full line of testing; they obviously thought she was a good candidate for research and asked us to participate. I did urge Maria to keep going back because I thought that if any breakthrough in treatment occurred this Institute was a place that would know. Columbia Presbyterian is one of the four main research centers in New York for Alzheimer's. Later, I tried to switch to NYU Medical, one of the other four. I was told that they were interested only in people with Alzheimer's not Lewy Bodies.

Dementia with Lewy Bodies can most simply be described as a combination of Alzheimer's and Parkinson's. Maria had lately complained about stiffness in her left arm. I did not connect that to the other problem she was having but it was evidence of a Parkinsonian dimension of the Lewy Bodies. Alzheimer's is the main form of dementia so that many people equate the two words. Lewy Bodies is the second most common form of dementia, but I found that many medical people had never heard of it.

Alzheimer's was first diagnosed in 1907 by Dr. Alois Alzheimer. For more than half a century, the disease given his name was thought to be a rare occurrence found among middle-aged people. Amazingly, no one made the connection between the "senility" of the elderly and this supposedly rare disease of people in their 40s and 50s. Hardly any research was done until 1980, a fact that I think is one of the great tragedies of twentieth-century medicine. Lewy Bodies was not diagnosed until the 1980s so that there is even less research on it than on Alzheimer's. The treatment of Lewy Bodies is difficult because of the physical



and mental dimensions. The drugs for one side of the problem can interfere with drugs for the other side. The relation of the two treatments must be carefully calibrated.

How much progress has been made in research on dementia is unclear. I had thought that a breakthrough might be just on the horizon. One constantly sees reports in the press of discoveries in the area. The only infallible test that a person has the disease is an autopsy. Despite all the advance in studying the brain, researchers are still at the beginning in trying to track the growth of plaques in the brain that destroy short-term memory. At the 2003 meeting of the main researchers, there seemed to be little agreement on where we are. Some of the experts were skeptical that the present drugs had any effect at all.

I never told Maria the whole story of Lewy Bodies. By this time the computer was beyond her so she had to rely on my reports. When she would ask me what I had read, I never lied to her but I also did not share all I knew. I think she was able to maintain the fiction that Lewy Bodies was not as bad as Alzheimer's though in fact it is worse. Whether she really believed that I do not know but I was not about to correct her false belief.

I know that research is important and I wanted to be cooperative with the Neurological Institute. Nonetheless, my primary concern was getting clinical help. Going up to 170th street every six months was not going to be enough. Maria was attached to her primary care physician of many years. The woman was always kind and available to give what help she could. I did not think she was the right person to help us. I was still innocent of where to turn.

#### Adjusting to the Horror (Dec. 2001 to August 2002)

After an initial shock, human beings have a resilient tendency to adjust to whatever the situation is. Conditions of life that a few hours, days, or months previous would have seemed intolerable can become the normal. One must try to live with whatever has become the day-to-day experience. There is a blessing in not having to look into the abyss at every moment of the day. There can also be a disadvantage in shortening one's perception, thinking only of managing the immediate situation. Both of us started living in what the literature would

probably call denial, but denial is not all bad (as Kubler-Ross acknowledged while placing it first in the stages of dying).

Maria sometimes would ask: “What is going to happen to me?” I would answer - truthfully: “I don’t know; no one knows.” Both of us knew that the long-term prognosis was horrible. For the care giver, the later stages of dementia are the worst to observe. For the patient, the earlier stages must be the worst, when one is fully aware of what is happening. For my part, I would sometimes think: This is the worst experience of my life. But then I would also think: This may be the first time in my life that I have done something really good. Hannah Arendt wrote that only really bad people have good consciences. That is, most of us most of the time live with conflicts of conscience; we constantly submit our motives and actions to re-evaluation. In this case, however, I knew exactly where I had to be, what I was called to do and why I was doing it. She would sometimes ask: Why are you doing this for me? That question had a very simple answer: I am doing for you exactly what I know you would do for me.

An extraordinary moment occurred in December 2001. Maria’s dearest friends invited her to a beautiful spot across from New York harbor called Breezy Point. I was not invited; it was a women’s only event which I fully understood. A dozen or more of her friends wished to celebrate the greatness of her life while she was still able to join in the ritual. From what I gathered later, it was an event of profound joy and sorrow. As her obituary in Newsday noted, not many people would have the courage to take part in what was essentially a goodbye to her life of sanity. Such an event could have been cruel, but the women knew Maria well and the ritual supported the mix of emotions that was inevitable. Maria knew that day exactly what was at stake but her only feeling later was gratitude for the care shown by the women. They could have waited a little longer, but they wanted to be sure that Maria could fully participate in the music, prayers and conversations of the day.

In an effort to keep things normal, I went ahead with plans to use our time-share in Aruba. We owned week one in Divi Village where we had gone many times. I thought it would be a good break from the winter cold and a way to forget for a while. I was just coming off twenty-one days of intravenous antibiotics. The oral drugs had not been able to dislodge the deeply buried Lyme disease; my last hope was intravenous drugs. The treatment succeeded in killing off the spirochetes, but

it also knocked me around. Still, it seemed like a good idea to go to Aruba to sit on the beach and eat at our favorite restaurants.

The week did not go well. Maria came down ill after a few days; it was diagnosed as food poisoning. Although she was not very sick, they recommended she stay overnight in the hospital. When I left at the end of visiting hours, Maria had already made friends with the half dozen other women in the ward, and they were pleased to have her with them. However, I got a call in the middle of the night that her behavior was disruptive, and she was demanding to talk to me. On the phone she described terrible things happening in the hospital and claimed people were trying to harm her. She had awakened in the night and being completely disoriented was frightened. I tried to calm her down and told her I would get her as soon as I was allowed into the hospital.

When I arrived, I found an exasperated hospital staff and patients in the ward who were upset at her behavior. It was several hours before I could get her released from the hospital. During that time, she was not making much sense. However, as soon as we left the hospital, she seemed to return to a grasp of reality. Unfortunately, I got sick the next day which did not help the trip. But Maria was always at her best when she had to take care of me during sickness. We managed to make the journey home, but I knew that was her last trip to Aruba.

As soon as we arrived back in New York, I set about with a more serious resolve to get some help. Her behavior in the Aruba hospital impressed upon me that her hold on reality was tenuous. I knew that the medical resources of New York City are almost unlimited. I had good health insurance in the university. But it was a mystery to me how to start. I tried at first to get in touch with one of the nursing professors (NYU's nursing division has a palliative care unit). It was in between semesters and I was not able to reach the people who might give me advice. I had the bright idea of calling the wife of one of my colleagues in the department. Cindy Hosay is a professor with a specialty in gerontology and was concerned about Maria. I knew she would at least sympathize with my plight and give me some advice, but she did better than that. She put me in touch with a social worker. What I first needed was an assessment of the situation, someone who could oversee the problem as a whole and recommend specific steps.

This social worker, Kathy, proved to be an invaluable aide. She visited the apartment every other Monday. She would not only talk over things with Maria, but she became the gatekeeper for other services we needed. She got us an appointment with a psychiatrist at Beth Israel Hospital who is an expert on Lewy Bodies. We began to see him on a regular basis and I finally had some confidence that the medicines were being carefully watched. On one occasion I made a separate appointment with him and he gave me a mini course on the drugs involved. He was candid in admitting that there were no universal protocols; he had to feel his way with each patient.

The other big move in January was dumb luck on my part. In thinking about a primary care physician for Maria I went over to where I had found one for myself. NYU runs a health care center for students just a few blocks from us. There is a small faculty practice at this center, staffed at that time by two young women physicians. I spoke to the one who was available; she was willing to take on Maria but said that her colleague, who specialized in gerontology, was better suited for the job. I hoped that Maria would feel comfortable with this energetic young woman, Alexandra. She and Maria hit it off immediately and I had no difficulty in getting Maria to leave her primary care physician.

From that point on, Alexandra watched every aspect of Maria's health. After prescribing a B12 vitamin, she called and said it would be better if Maria came in every first of the month to receive a B12 shot. Each month when we came in, Maria would get a big hug and a generous amount of time for an examination of every aspect of her health. On two occasions, Alexandra phoned on a Saturday evening to recommend a change of treatment. On one of those occasions, she tracked us down in Montauk, called the pharmacy in Montauk which was closed, and finally found a pharmacy in East Hampton so that we could pick up the prescription first thing on Sunday morning.

One striking thing about many of the people we dealt with was they weren't just in the work for the money. Alexandra mentioned to me about six months into the shots that she had just discovered it was not covered by insurance. She did not like to ask, but would I pay for half of the expense already incurred. I said I would gladly pay the whole bill; she should not have to subsidize the cost of Maria's treatment. Similarly, with Kathy, the social worker. She mentioned after about six months that she had not been paid yet. I was shocked, having assumed that she

was receiving money from the insurance company. What really shocked me was that she would travel to the apartment, sit with Maria for an hour and supply me with useful information while not getting paid. We fixed it up and got the proper papers filed. Filing health care claims and following up on delays and mistakes can be almost a full-time job in itself.

With the social and medical aspects of Maria's illness being monitored by competent people, I could turn my attention to two other areas: nursing homes and legal affairs. I did not want to be suddenly forced into deciding about a nursing home during a future crisis. I wanted to get a sense of what the options were, even if all the possibilities were somewhat depressing. Maria was willing, if not enthusiastic, about taking a tour of a few nursing homes. I picked out two of the best in Manhattan. An inviting aspect was that each was within fifteen minutes of where we lived. However, both of us had bad vibes as soon as we walked into them.

I must admit that if you are not used to nursing homes the first impression is almost sure to be a shock. These two homes were clean, well-run, and equipped with numerous services for the patients. They still felt like warehouses. A lot of effort went into putting a happy face on sad and lonely lives. There were jarring elements, such as a loudspeaker system that would drive me crazy. The first place required documented proof that we had \$100,000 in ready cash. The visits were worthwhile for us and on the whole not negative. But I hesitated before arranging visits to other places.

Maria would sometimes say: "Don't put me in a nursing home." I would reply: "I am not going to put you anywhere. Whatever is decided we will decide together." I was not sure I would be able to keep that promise but I would do so if it was at all possible. Sometime during that year, I received a message via a friend from the director of a nursing home in Brentwood, Long Island: "If ever and whenever Maria needs a nursing home, she should know that she has a place here." Nothing was more helpful to my sanity than receiving this message. I knew with Maria's history that no place would be as compatible as Brentwood. Through the next year and a half, having this available option was a great relief.

On the legal front, I surmised that I needed an elder care lawyer, someone knowledgeable in the increasingly complex legal world of the aged, sick, and

dying. My total experience with lawyers was making out a will in the early 1990s. We went to a lawyer we knew nothing about except that he came to the aid of a group of Buddhist nuns we knew. How does one find the right lawyer? I looked up elder care lawyer on the Internet and I was faced with one thousand names in Manhattan alone. I figured my best approach was to call Maria's cousin, Michael O'Brien, a lawyer on Long Island; it was the right move. Michael was particularly devoted to Maria and proved to be extraordinarily generous with his time and help during the subsequent three years. He said he knew just the right person that I needed.

I thought an hour's consultation to answer my questions would be enough, but I was naive about lawyer work. It required many meetings and several months before we left with a dozen legal documents (last will, living will, power of attorney, health care proxy...). Maria came to the first few meetings and could express her views. She did not understand much of the proceedings, but neither did I. Michael insisted on coming with us to make sure we understood all the legal talk (he would not hear of taking money for all the time he put in).

I was trying to avoid having Medicaid take over my life (sixty percent of people in nursing homes are on Medicaid). Of course, at the current New York area average price of \$10,000 per month, everybody except the very rich would eventually run out of money. One of the first things the lawyer recommended was that I should get maximum coverage of long-term care insurance for myself (we each had modest policies). I was surprised I could get it at my age but if you look at nursing homes you can see that not much insurance money is being paid out for men. The coverage for myself was to protect her in case I went into a nursing home first. That did not seem implausible to me. At that time, I thought it was still likely that she would outlive me.

In the Spring of 2002, I considered quitting my job. Maria did not want me to and frankly neither did I. If I were to quit work, I would have more time to attend to her, but I feared that the world would close in on us. Having a job gave me perspective and periodic relief. Of course, I could not have kept most jobs but being a university professor has its advantages. My office and classrooms are about a three-minute walk. During the Spring of 2002 I could still leave her alone for two hours at a time. She came to some of the classes, not as visiting teacher but as interested student.

An incident in April pointed to the difficulties of her traveling alone. I had gone to Montauk on the train; she was to follow on the bus. When the bus came in and she was not on it, I panicked. I got no answer when I called New York. I pictured her lying unconscious in the apartment or wandering the streets of Manhattan. Without thinking to leave a note, I took the next bus back to New York. Her bus had been delayed and detoured. When she arrived and I was not there she immediately called the police to report a missing person. Two cops from East Hampton took the information and calmed her down somewhat. As soon as I entered the apartment, I had a call from the police. The message: "Your wife is looking for you." The department at NYU was curious as to why the East Hampton police were looking for me.

The next week I got two cell phones so that nothing similar would happen again. However, she was intimidated by anything technological and never became adjusted to the cell phone. I would show her repeatedly that she could reach me (and some of her friends) by pushing one button on the speed dial. It was still too complicated. The part of the brain that handles pushing even one button was no longer working.

In July 2002, I went to Norway for the ISREV conference. I would be gone for just a week and Maria's longest and closest friend, Joanmarie Smith (a.k.a Dulcie) came to Montauk to stay the week with her. Dulcie and she had a history of fifty years; Dulcie could do things with her that I could not. Although Dulcie has lived in Ohio for more than twenty years, she and Maria remained as close as ever, talking on the phone almost daily. I had no misgivings leaving Maria with her dearest friend who could handle whatever came up. I called each day from Norway and found Maria to be lively and enthusiastic. The only peculiarity was that she kept referring to the nuns taking care of her and the two Dulcies who were there. That seemed like a minor slip of the tongue, but it presaged another stage of development and a confusion about me.

#### A Turn for the Worse (August 2002 to Dec. 2002)

One of my most vivid memories is of a Sunday evening in late August 2002. We had been watching the last round of the PGA tourney. Suddenly, with no provocation, Maria did not know who I was. I must have reacted strongly and tried

to argue with her. That made things much worse. She said she wanted to leave and go home; I insisted she could not leave and that she was already home. At one point I called Dulcie in Ohio to see if she could talk her through this confusion. That helped a little but she still wanted to leave. When I would not let her, she asked me why I was keeping her a prisoner. It got so bad that she asked me if I was going to kill her. I don't know how we got through the night. I was hopeful that by the next morning she would have forgotten the whole incident.

Although she was calm in the morning, she still did not know who I was. The mother of a close friend had died that weekend, so we went to the wake on Staten Island. On the ferry boat, at dinner and in the funeral home she still did not know who I was. I said to my friend: "Something seems to have snapped; I think I have lost her." On the cab ride back home, she said it was amusing that all the people there thought I was Gabriel Moran. I suggested to her that perhaps they were right but that did nothing to convince her. The confusion continued until Wednesday when I went back to Staten Island for the funeral; she preferred to stay home. When the funeral took longer than I had anticipated, I called to let her know I would be late. She recognized my voice on the phone and said excitedly, "Where have you been for the last four days; I have been looking for you." The recognition carried through when I arrived in person.

That was the first of numerous occasions when I had to cope with her confusion of who I was. When I had first heard that hallucination was part of the disease, I assumed that I could be her bridge to reality. Instead, I was what she hallucinated about. The psychiatrist said it was fairly common, a form of hallucination called reduplication. It is directed at the people who are closest. Only with myself and Dulcie did this confusion seem to occur. Maria could recognize by name people she had not seen in twenty years. But sometimes in the blink of an eye she could not recognize me.

The fortunate thing was that she usually got along with all of us. After the first incident, I learned how to react and simply go with wherever she seemed to be. Neither reasoning nor facts made any penetration once she became convinced I was another person. The metaphysics of the brain constantly surprised me. We would seem to be having an ordinary conversation and she would suddenly say: "You never married did you?" I would calmly answer: "Yes, I did; I married you at the NYU Catholic Center." She would just smile and listen, wondering perhaps



at my confusion. Once she asked me at breakfast where I had slept the night before. When I said in the bed next to her, she said: “There were three of us in the bed?” I assured there were just two of us.

At times, she almost seemed to be on the inside of a playful joke. She told the psychiatrist that she could not use the toilet when she wanted because we had a public bathroom that she shared with ten men. I hastened to tell the psychiatrist that was not the case. In subsequent visits he would ask her how many men she was now living with. With seeming playfulness, she would say four or three. I had several names; her favorite was one that went through a couple of evolutions before ending as “Bonaventura.” She always got along well with kindly Bonaventura. I sometimes had the feeling that she was seeing a younger version of myself, someone she knew from thirty-five years ago. She told me one day about a nice young man who had taken her to the subway. When I told her that I was the one who had accompanied her, she said, “Oh, no; he was a young man.”

One day she said to me: “How do you know I have this disease?” I replied: “I was with you when we received the diagnosis.” She said: “No you weren’t, I went with my mother.” One’s instinct might be to correct the person and say: “Don’t be foolish; your mother has been dead for ten years.” Such a response could cause the person great sorrow. It might be like hearing the news of her mother’s death for the first time. Like others confronted by a person living in another time zone, I learned never to force my world on hers, wherever in the past she was.

Only on a few occasions did her confusion become a situation difficult to manage in public. I finally recognized that travel often brought about the confusion and the psychiatrist recommended that we not go out to Montauk. What she needed was stability and a consistent environment. Although our house in Montauk was a place where she was at home, the travel there caused confusion. Once on the bus she became extremely agitated because she had left her husband behind. Why had I rushed her on to the bus without waiting for him? I had to physically restrain her from getting off the bus in Southampton. She wanted to ask if anyone had seen her husband. A few minutes later when the bus ride continued she went to the toilet at the back of the bus; on returning to her seat, she recognized the back of my head. Where had I been, she wanted to know. All my talking to her had brought no conviction at all; one glance at the back of my head did the trick.

A particularly difficult incident happened in a hotel in Philadelphia. Maria had been active in a professional organization called the Association of Professors and Researchers in Religious Education. The meeting that year being an easy ninety-minute train ride from New York, I suggested we go. Maria was happy to do so. I knew that the women in the group would be glad to see her and would give her affirmation. They did so beyond my expectation. The difficult part came in trying to check into the hotel. After the pleasant train ride, she suddenly did not know who I was during the five-minute cab ride to the hotel. She refused to take a room with anybody except her husband. I was lost as to what to do. She finally relented enough to wait in the room until her husband arrived. Then she recognized me when I was speaking at the front of the hall and she was in the audience.

One of my most painful memories relates to Thanksgiving that year. My two sisters brought a complete turkey dinner with them down to Montauk. We had a wonderful meal and lively conversation. But after the meal, Maria took my sister Dotty aside and said: "Can you get a message to my husband; I don't think he loves me anymore and he seems to have abandoned me." Such moments were paralyzing for me. They were indicative of great suffering on her part. I was in some sense the cause of the suffering, but I was utterly helpless to relieve it. The only recourse was patient waiting. By the next day she might have forgotten that she said that. For me, life became unending surprises and constant learning of how to respond to whatever might suddenly be the reality.

#### The Year of Living Dangerously (Jan. 2003-Dec. 2003)

When I reflect on the year 2003 I am most struck by the many possibilities for disaster that we avoided. That result was due in part to my watching out for terrible things but often it was just a matter of luck that disaster did not strike. What I feared was that Maria would have a crippling accident. As any parent or a care giver of a disabled person knows, one must balance control and freedom. I did not want to hover over her every move but that meant allowing that something untoward might happen. Many Alzheimer's patients fall and break a bone, spend time in a hospital, and then are sent for rehab to whatever nursing home is available. The family's choice is limited once this process has begun. I was determined not to follow that route.

We were still able to go out to a movie or a restaurant. In January we went to a theater up on Broadway. I had an attack of vertigo coming out of the theater. I have no idea how we got home because I could not keep the pavement from moving under my feet and I was violently sick to my stomach. I had to lean on her to help me get home. We must have been a pretty picture making our way down those ten blocks of Broadway. But like what happened in June that year when I got seasick coming back from Block Island, Maria's instincts for taking care of me shifted back into operation.

I realize now that I was taking chances because I was lulled by what seemed to be normal behavior most of the time. The drugs she was taking were apparently successful in stabilizing the situation. That is, the decline was very gradual until the end of 2003. The danger in being so close to the situation is that one does not see – perhaps does not want to see – the small changes and the imperceptible descent that is occurring daily. Managing the drugs was a major task. From the start I had to watch over the ingestion of every pill she took, but that was just part of the daily routine.

A bigger problem was the apartment's layout and location. We were living just off a street bustling with buses, cars, and crowds. The building was constructed in the 1800s. Some aspects of the apartment were very appealing (the high ceilings, the thick walls). But the major problems were the lack of an elevator and the design of the bathroom. I was constantly warned about the stairs, that as her condition worsened she was liable to fall. Remarkably, she never had the least problem or even hesitation with the stairs right up to the end.

The bathroom was another story. Without going into all the details, suffice it to say that eventually life revolves around the bathroom. I asked the contractor for the building if he could build in guard rails. He thought it would require smashing down the wall into the next apartment. He was reluctant to do anything for which he might be legally responsible if a fall occurred. I eventually fashioned my own safety devices, learning as I went along. At present, sixty percent of Alzheimer's patients are being cared for at home. In most cases, a man is being cared for by his wife. I cannot imagine how they manage the physical part. Maria was barely a hundred pounds, but I was often at my limit in trying to move her about. I also have increased respect for the twenty thousand home health care workers in New

York City. They are not paid much over the minimum wage for work that is both physically demanding and mentally exhausting.

By 2003 it was apparent I could no longer leave her for the two hours I was in class. Kathy, the social worker, investigated the visiting nurse organizations in mid-town Manhattan. None could provide the flexibility I was looking for. Kathy put up a notice in St. Francis Xavier Church asking for help. That turned up a person perfect for what I needed. Delores was a retired woman who lived a few blocks away. She was the kind of help that no amount of money can buy. She was willing to come for whatever hours were needed. She and Maria immediately struck up a friendship and Maria felt completely at home with her. The two of them would sit quietly listening to music. Or they would go to Delores's apartment to visit with the two new dogs she had. It was great companionship, neither more than that nor less.

I had to make sure that Delores did not leave before I got back, especially if it was in the evening. A couple of times when I was delayed a few minutes, Maria was getting ready to go out looking for me. Fortunately, she was stopped each time by women in the building who waited with her.

One of my most frightening moments occurred in the middle of a Monday afternoon. We had hired a cleaning woman to come in every other Monday. I thought it was safe to leave Maria because she had company. When I came back from school, Maria was not there. The cleaning woman was not at fault; I had not given her any warning or instructions. Given the amount and pace of traffic right outside the door, I was fearful of her being on the street.

I rushed up and down all the streets of the neighborhood but found no trace of her. I went over to the health center, thinking that was one place she might have headed for. Actually, that is where she was, but I looked only in the waiting room and Alexandra had taken her inside. I went back to the apartment not knowing what to do next, but she showed up just a few minutes after me. She was not upset in the least; she simply thought she was keeping an appointment. I was relieved that she could find her way over to the health center on Broadway and return to the apartment. I also felt guilty for neglecting to get an ID bracelet which many Alzheimer's patients wear.

The most remarkable thing Maria did that year was to take four trips to Delaware, Ohio, to visit with her friend, Dulcie. Both I and Dulcie were amazed at her willingness to make the trip the first time and then casually to repeat it. We used the same flights on the same airline for stability's sake. I would bring her to the door of the plane at LaGuardia and Dulcie would meet her at the door in Columbus. The airline people on board never had any problem. And I discovered that the airlines are very ready to provide wheelchair assistance. Just once when they did not have enough wheelchairs at the door, she took off on her own and I found her making her way through the labyrinths of LaGuardia Airport.

Dulcie and she would not do much except sit and talk; they could do that endlessly. Maria was content to go each time and content to return. I realized on the last trip that I should have got on the plane with her and that I could not let her go alone again. But another trip was never possible. Making those trips must have included some shaky moments for her, especially the ninety minutes in the air. Nevertheless, I think the travel gave her a boost and released some of the spunky self-confidence she had possessed when healthy.

The other big help to me during that year was that my sister, Mary (a.k.a. Sr. Madonna) took the train down from New Hampshire five times to stay with Maria over a weekend; I went out to Montauk and slept. Mary had headed an order of sisters for many years and is comfortable among the sick and aged. She is an unusually patient, kind and understanding person. Not surprisingly, she and Maria became good friends. In addition to Dulcie, my sister was the only person I was confident could handle the situation. To stay with Maria for a couple of days was to ask too much from most people. My sister managed effortlessly, and Maria loved having her company.

There was more to do in New York City than in Delaware, Ohio, so the two of them did a little exploring. Maria insisted each time that they have a pedicure from the Korean salon next door; Maria had the idea that a pedicure has roots in the New Testament. I think a pedicure was about the last thing my sister would have got for herself, but she always graciously accepted Maria's gift. And occasionally Maria could still assert her native know how. Once they went downtown to visit the World Trade Center site, an area that was still a traffic muddle. When my sister asked a cop where they could get a cab, the cop said they would have to walk

several blocks north. But when my sister and the cop turned around, Maria was in the middle of the street with a cab she had just hailed.

In the Fall of 2003, Cindy Hosay, who had been helpful in getting me started, gave me the name of a music therapist on the upper East Side. The woman and her husband do wonderful work with people who are disabled, including people with dementia. Maria, as I noted earlier, was a musician, an expert pianist and singer. I had often read that music is one of the last things to go in people suffering from dementia. I thought that music therapy would be especially appropriate in Maria's case; and it was.

I bought a keyboard so that she could play at home. In my zeal to get the best instrument, I bought a keyboard that was technologically intimidating for her. When she was later in the nursing home, I bought a much simpler version of the instrument which is where I should have started.

The therapist, Helene, was almost infinitely patient in trying to get her to perform some simple exercises. I used to sit watching for the hour and I learned lessons about teaching. Maria struggled with any kind of sequence or simple pattern. On the other hand, she could run through a tune from Oklahoma or a Latin hymn from her childhood. Helene was startled by Maria's ability to play a whole song from memory. One of the marvelous things about this teacher was that she would simply take her lead from the student, a trait especially important when dealing with dementia. Maria's ability to play from memory as she had all her life did not surprise me much. As with other things but especially with music, the loss of short-term memory can leave parts of long-term memory intact.

We have learning from research that the plaque in the brain destroys specific functions and activities. People who have no short-term memory may appear stupid, but they are not. They can still have a deep appreciation of the arts. The New York Times recently had a story in the Sunday Arts section on Alzheimer's patients. It referred to a program at a local museum for these patients. The writer sounded completely mystified by the obvious capacity for art appreciation shown by the patients. It is not such a surprising phenomenon; another part of the brain continues to work well despite the loss of some functions.

During 2003, Kathy got me in touch with an adult day care center in the West Village. She did some work there and promised me that it was a good place for Maria to go. Maria and I went together the first time and she agreed to go back on each Wednesday. A car would pick her up at the door in the morning and return her in the afternoon; they would call ahead to check that I was at home. A varied program of music, art and physical therapy was provided by a staff who could not have been more cordial and hard working. They loved having Maria because, despite her illness, she was bright and relatively active. For example, she made friends immediately with a young man who had suffered a severe stroke and could not speak. I felt awkward in his presence and did not know how to communicate with him. I don't think Maria found it to be a problem; she was her usual self and brought him out of himself.

I was hoping that she would like to go to the Center. I thought it was good for her to get out of the apartment and engage in activities that I could not provide. And, frankly, it was a relief for me each Wednesday. She soon became resistant to going; she continued to attend but with reluctance. It had nothing to do with the treatment by the staff; to a person, each of them was wonderful with her. I guessed that the reluctance stemmed from the vision that she was getting of what lay ahead for her. Many of the people who came to the center were at an advanced stage of dementia. Maria was not there yet. But I think that toward the end of 2003 she had begun to sense that the future was closing in on her.

#### The Year of Living Inside (Jan. 2004 to Dec. 2004)

Although the drugs had seemed to work fairly well for almost two years, they suddenly seemed to be ineffective toward the end of 2003. I realize there may have been other factors at work that brought about the change. In any case, I noticed a sharp change for the worse in Maria's behavior. Both on the physical and the mental sides there were serious changes that made living in the apartment dangerous. I had assumed that my next step was going to be home nursing help around the clock. But I started to wonder if even that would be adequate for the developing situation.

I arranged for a visit during the first week in January to the nursing home in Brentwood which is called Maria Regina Residence. We went out on the train and were given a tour of the place. Maria had lived on the property for two years when

she was a novice; she had also taught there and visited many times. Her mother had even gone to school there almost a century ago. It was a place Maria was very comfortable with, and many people in the facility, both staff and residents, knew Maria. We were therefore received with warm friendliness. Eating dinner from a good buffet in a pleasant dining room was an attractive feature of what we saw. I was aware that there were sections in the building which we did not see where the residents were at a more advanced stage of disease. But the attitude in the place was openness, efficiency, and compassion. The best thing was that we both had the same impression.

At breakfast the next morning, Maria's first statement was: "It is not a question of if but when." I was surprised at her succinct statement of where we were. Nothing she could have said would have provided greater relief for me. She was taking away the burden I would have felt if I had to try persuading her that going there was in her best interest. We discussed our feeling about the place which was very different from our reaction to the other nursing homes we had visited. We did not decide about time; I hoped to maintain my promise to do whatever was necessary when the time arose.

The director of the nursing home, Helen Clancy, called me the next day. I think she had seen something that I could not see at that time. She asked if Maria was planning to come at the beginning of the next month. I said, "Oh, no. I was thinking about the future, maybe six months or a year from now." In the course of that month, however, I came to grasp that the situation was fast becoming intolerable. I don't know if the change for the worse was precipitated by the prospect of going to the nursing home. Maria did tell my sister – but not me – that she knew she should be in a nursing home because the burden was too great on me.

An incident at the end of the month sealed my decision to move more quickly than I had thought just weeks previously. We went out for a walk in the neighborhood, and everything seemed peaceful and normal. But on the way back she suddenly darted into the building next door. When I tried to get her out she started screaming that I was attacking her. Fortunately, the super and the janitor arrived, and they immediately recognized the situation. Maria trusted the janitor who offered to take her home. She kept screaming to keep me away from her.



When she had been taken back to the apartment, I sat outside on the steps waiting for her to cool down. But she came out and walked up the stairs without saying anything to me. I figured she was safe up there and would eventually have to come down. But she knocked on a door and the woman took her in. Not knowing what to do, the woman called the police. The ID Maria was carrying gave Montauk as her address. When I saw two New York City cops go by me, I suspected what they were there for. When one of them came out of the woman's apartment on the third floor, I told him that Maria lived on the next floor down.

The policemen could not have been kinder both to her and to me. They spent about twenty minutes coaxing her back to the apartment, getting her a glass of water and making sure she was safe and calm. After I sat outside for an hour or more, I went into the apartment and she did not give the impression that anything unusual had happened. The incident is the kind of thing which care givers regularly confront. Looking back on the experience, I cannot find anything I should have done differently. I was just lucky that it did not turn out worse. I could have been taken in by the police for questioning; that would not have been unreasonable. She could have suffered serious injury. I concluded that "the when" had arrived.

I arranged for an entry date at the nursing home. Michael O'Brien and his brother Kevin insisted on driving us out and they stayed until we were settled. I said in Maria's eulogy that the day we arrived we were received like royalty. Not many people enter a nursing home with such an upbeat tempo. I said that the sign on her door which read, "Welcome to Maria Regina," could be read in two ways: Welcome to the place whose name is Maria Regina; or Welcome to the woman named Maria who will be treated royally.

On that day and in the year that followed she was given the best care possible. I cannot express how grateful I am for how she was treated. The staff listened to my suggestions, such as giving her the pills with yogurt rather than apple sauce or giving her regular massages of her neck and back. I was allowed to brighten her room with some of her favorite art pieces, to bring a CD player and hook up a telephone recording device. Many people phoned her (Dulcie almost every day). Surprisingly, she was able to function on the phone even when she was barely able to communicate in person. On the last day of her life, as her consciousness ebbed,

I was convinced she recognized Rosemary's voice when she called from Melbourne.

For a good while Maria managed to remember most of the faces and names of people who visited. She had a steady stream of visitors; Michael O'Brien came faithfully every week. Good friends such as Kathy Sperduto and Joan Grace, neither of whom was in the best of health, came when they could. Her dear cousin, Jim Tunny and his wife Betty Ann, were especially solicitous. Friends of mine, including Kieran Scott, Anthony Fasano and John Grieco, were supportive and on the scene. But on October 1, 2004, John Grieco, a friend of forty years dropped dead. He had been a constant support for me and a great friend of Maria's. I was devastated by the loss.

The one drawback with the nursing home was that Brentwood is about in the middle of the traveling distance between Montauk and New York. I had to allow about four hours round trip either driving from Montauk or taking the train from New York. However, in some ways I now had more time even if I spent eight or ten hours in visiting her. I considered getting an apartment in Brentwood but I decided that the train from New York would be less disruptive of the job I was trying to keep. I had some regrets later that I did not move. When she could not feed herself, I would have liked to have been there every day at noon instead of the every other day I tried to maintain. Helping a person to eat takes time and attentiveness. When she was in the hospital, one of the staff asked me how I got her to eat whereas they could not. I said: "Well, the first thing is it takes half an hour." Hospitals, rehab centers and nursing homes do not have the personnel to spend that much time with individual patients.

Until July, Maria could manage her own eating and had a healthy appetite. I had looked forward to the Spring and Summer when she could get out on the extensive grounds, even though by the late Spring she was confined to a wheelchair. One pleasant aspect of each day was going down to the chapel at 11:20 AM for the Eucharist and then going to the dining room for a leisurely dinner. I went more often to church than I had in years. It was a restful and comforting experience. With many people in wheelchairs or struggling with various ailments, the liturgical ritual of the Catholic Mass provided a community bond.

Most of the residents were nuns; the place had been built by the Sisters of Saint Joseph for their own use in the 1960s. With only a few modifications, they were recently able to open it to the general public. I could understand it if some people would find the atmosphere of Catholic piety too confining. But Maria adjusted easily to it. There was no pressure on anyone to conform to a religious code or a set of practices. I felt that as Maria withdrew from this world, she was often praying and in touch with another dimension of reality.

The physical therapists were wonderful with her, as were the woman who did her hair and the woman who did her nails. Such small touches brightened the environment. The woman who directed the second floor's operation was a model of efficiency and kindness. I got to know the place pretty well from sitting for many hours watching the nurses, the aides and the people who cleaned. Most of us most of the time can shut out of awareness the inner workings of nursing homes but the work there requires patience, skill, and dedication. The pay will never be consonant with the importance of the work for an increasing part of the population.

When I had previously been in nursing homes I was ready to climb the walls after thirty minutes. Here I was surprised that I did not find the hours to be a drag. I found I could sit in silence for long periods. Of course, I was always aware of my situation in relation to hers. I could not imagine how she passed the time. She could not read or did not wish to read (she who used to grab the crossword in the Times every morning). Even television – the pacifier of babies and the aged – did not interest her. I tried various things but a set of video tapes of her favorite program, *As Time Goes By*, was one of my few successes.

Throughout her illness and during the time in the nursing home, Maria showed little anger. One of the best chapters in Kubler-Ross's On Death and Dying is the chapter on anger which warns care givers to expect anger and not to take it personally. I sometimes thought she (and I) might feel better if she screamed and threw things. She remained remarkably calm under almost all circumstances. When she went to a hospital or clinic for a treatment, it involved being lifted up, pushed around, strapped down, bumpily transported, but she remained serene. I, not she, would get furious when she was left on a stretcher for an hour or more in a waiting room. Her unlined face retained a strange beauty despite all she suffered. Some friends who dropped in told another friend that what struck them when they walked into the room was how beautiful she looked. It was therefore not mere

blindness or bias on my part that she looked as beautiful at the end as she did the day we first met.

In October I received a call from a surgeon asking for my agreement that she have surgery for a pressure sore. The sore which was there from before she had entered Maria Regina had not responded to treatment. The surgeon said it was necessary to operate; otherwise, it could mean her “demise.” I obviously had to agree to the surgery. Until that time, I still did not understand the seriousness of a pressure sore; I thought it was just a bother and an irritation. When Christopher Reeve died that month, the press carried stories that most people with dementia die from pressure sores that become infected.

I was told that she would be in the hospital for seven days and in rehab for fourteen days. What happened was that she was in each for about seven weeks. Neither place was bad, but they were not as comfortable as the nursing home. I used to say that one’s expectations have been shortened when all one hopes for is to get well enough to go to the nursing home. After she was many weeks in the hospital a surgeon said to me: “We want to get her out of here because the longer you stay in a hospital the more problems you develop.” I thought that was surprising if somewhat depressing candor about hospitals.

When it came time to move, I had a choice among a few rehab centers that had the proper machine to help her healing. My best choice was a place in East Patchogue, Long Island, which added a few more hours to my travel but which seemed a decent place. After almost two months of treatment with machines and drugs, she showed little progress. I did not think it was anyone’s fault; they did what they could. I was asked to agree to insertion of a feeding tube – a temporary tube – to improve nutrition. I would not have agreed to a permanent tube but after a while temporary tends toward permanent. At one point I looked at her with five different lines running into her body. I had approved each thing separately, but I began to wonder if the total result was just a form of torture.

The house physician was a nice enough man but not much involved with her case. When I asked him in early December when she might be able to leave, he replied quite casually: “Oh, I don’t think she will ever leave.” His candor shook me up. Until then I was concentrating on each day while I waited for the rehab to be over. His remark forced me to start considering that if the wound from the surgery had

not healed then the end might be near. My sisters had seen this in October when they visited Maria in the hospital but for me it was a sudden awakening in December.

### The Final Goodbye (Dec. 2004 to Feb. 2005)

On Christmas day, 2004, I knew that Maria was dying. I had gone out to the rehab center with Dulcie and with Elaine Roulet, another close friend of Maria's. This pair with their outgoing friendliness brought cheer to any room they entered. I knew that if they could not get a rise out of her, then she had passed a point of no return. When we entered the room, Maria closed her eyes. Whether the movement was voluntary or not, it was shockingly different from the past, even a few weeks earlier, when the three of us visited her in the hospital. We shared Christmas day with her but with little response on her side.

I talked to the house physician again. He knew a little more about her case now. His prognosis was more guarded but no more optimistic. I asked him if he had communicated information to her primary care physician, but I found that he did not know who that was. I offered him the phone number so he could call. I must admit I was still naive about the communication of information among health care providers. It finally came home to me two weeks later when I asked one of the surgeons about the antibiotics Maria had been taking. The surgeon had no knowledge of that. When I gave the name of the person who prescribed the drugs to the rehab center they did not recognize the name. The light finally dawned: I was the only person who actually was aware of all the parties involved. Unless I functioned as the link, these people did not talk to each other.

At 10 PM on December 31, I got a call from a nurse in the rehab center. The nurse said Maria was not responsive. Did I want them to send her to the hospital? My question was how was I supposed to judge that? I asked: "Can't you call the attending physician to decide that?" He finally got back to me and we talked it out. We agreed that she was not likely to get much attention in a hospital emergency room on New Year's Eve. She was probably better off where she was.

The next week her primary care physician called. Dr. Ryan Cahill was a fine, caring physician serving the nursing home. He had always been straightforward with me, doing what he could for her but honest about the limitations of any

treatment. I asked what he thought, and he replied: “Tell me what you want and then I will tell you what I think.” Not many physicians are that willing to listen. I said that the wound had not healed. One choice was to go back into the hospital for more surgery but that was unlikely to succeed. More surgery and antibiotics would probably just add to her discomfort. However, without further surgery she was likely to develop an infection. He agreed.

Then I asked him to describe to me what it is like to die of sepsis or septic shock which he did. He assured me that pain could be completely controlled. We agreed that she should return to the nursing home and be given palliative care. Good Shepherd hospice was contacted to give us additional help in keeping the patient comfortable. When she was returned to the hospital she was given a quiet room on the first floor with ready access to any service she might need. Staff from the second floor where she had previously been came down to see her.

She stopped receiving nutrition because her body could no longer tolerate it. There are acrimonious debates in this country that surround “the removal of the feeding tube.” The tube is not actually removed; nutrition is simply halted. Some people scream murder when there is such a move; they claim the patient has been starved to death. There are some debatable cases but most of the time the inability to take food is a sign that the body is preparing for death. In any case, the cause of death is not “starvation,” an inappropriate name for allowing the person to die. In Maria’s case continuing the feeding would have worsened her condition because the body could not absorb the nutrition..

When I arrived on Saturday, January 29, the nurse told me that Maria probably had only a few days to live. Obviously, I should have known the end was coming soon but it still caught me by surprise that it would be so quick. I moved into the nursing home, staying in a guest room that they had provided whenever I wished to stay overnight. My sister and brother-in-law came down from New Hampshire and the three of us went to the funeral home to make arrangements. Afterwards, I would be relieved that all that preparation was in place.

I did make one quick trip to Montauk to pick up a few things that would be needed. On the trip out, there was an incident that touched me deeply. There is a friendly conductor on the Long Island Railroad whom I often meet. We exchange pleasantries; he often checks what I am reading or what movies I have seen. On

this day, I blurted out “my wife is dying”; he was the first person I said that to. He finished collecting the tickets and came back to sit and talk with me for an hour. One does not expect such compassion from a railroad conductor. It was one of numerous gestures of kindness I experienced from friend and stranger alike.

On the morning of February 1, I was waiting for Dr. Cahill. When he arrived and I asked him what he thought, he replied: “You have been here more than anyone; you tell me.” I was again surprised by his willingness to listen, rather than play the expert. After he heard what I had seen in the past few days, he checked her chart. When he saw that her kidneys were essentially closed down, he said she could not last long. I stayed with her throughout the day trying to aid her breathing. Her lungs were filling with fluid. Listening to a person dying of pneumonia is disconcerting. There is obvious discomfort for the patient that cannot be removed but no apparent pain. I went out briefly for dinner and when I came back the breathing was more labored. I did not recognize the gurgling of a dying person. A nun who had great affection for Maria stayed with us. She recognized better than I how close death was. She had seen it dozens of times; I had little experience.

I held Maria and tried to keep her mouth clear but, of course, my efforts were futile. When the staff tried to suction the lungs, I thought for a moment that her breathing had suddenly improved and then I realized that she had stopped breathing. The time was 9:50 PM; the last moments had been relatively peaceful. Two other nuns came in to pray and to provide immediate assistance. I called my sister and her husband who had gone over to their motel a few hours previous. They immediately returned and stayed with me until the funeral home came for the body.

#### Immediate Aftermath (Feb.2005)

The next day I was mostly in a daze. Most of the funeral arrangements had been made and I had plenty of help in attending to whatever had to be done immediately. By the middle of the day, there was nothing more for me to do in the nursing home so I went into New York. I was waiting for a call from the funeral home which was trying to arrange an autopsy. Michael O’Brien had asked me if I would have an autopsy, concerned about the presence of Lewy Bodies in the family gene pool.

The funeral home had difficulty finding an available pathologist. Rather than sit alone in my apartment, I went over to school and met my graduate course. I could have canceled the class; the students were probably surprised that I came. I did not think of it as heroism. I simply found that teaching that day and throughout the semester was therapeutic for me. The students were wonderfully supportive and it gave me a chance to talk out my feelings. At about 10 P.M. that evening I got a call from a pathologist. She said she was willing to perform the autopsy the next morning. However, she needed a check for \$4000 dollars before she would begin. Early next morning I was on the Long Island Railroad check in hand.

The delay for the autopsy pushed back the wake until the weekend and the burial until Monday. That schedule was probably a fortunate one because it gave time for people to read the notice in the papers and to travel from great distances. The day before her death I had written three separate obituaries. The first obituary was for the New York Times. I knew that it was a long shot getting a story into the Times. Our wedding had gotten a write up but that was when Tom Harris was with the paper. As it turned out, I gladly paid for the notice in the Times that would be read by many people in New York and beyond. In the second case, Newsday did not use the obituary that I had written for them, but they assigned a staff person to write the story. They had a fine picture taken on our deck in Montauk when they had done a feature on Maria. I was delighted with the picture and story that they ran.

The one newspaper I was sure would run a story and let people around the country know of her death was The National Catholic Reporter. I called the paper immediately but it took two days before I got through to the editor. He seemed interested and I immediately e-mailed the obituary that was tailored for that paper. They did not even run one sentence acknowledging her death. I repeatedly tried to get an explanation why, but with no results. I am still angry at that newspaper. Six months after Maria's death I was still getting letters from people who were just finding it out. The organizations we belonged to tried to spread the word but it did not circulate to everyone who would have been interested.

I knew that most people coming to the wake would be expecting the standard Irish Catholic format. If the choice were just for myself, I would not have gone along with an open casket and many other features. I allowed the body to be embalmed though I consider the practice to be weird. A steady stream of people came for the two days. I met some people that I had not seen in twenty, thirty or forty years.



I had chosen a church for the funeral because of a helpful suggestion by Padraic O'Hare. The pastor in this church not only knew Maria but would be amenable to having what we wished for the burial service. I went over to the church with Dulcie and my sister Mary to talk with the liturgist about music, prayers, and the rest of the ceremony. Elaine, the liturgist of the church, had a more coherent picture of how to handle things than any of the three of us. Thus, the funeral was done with a beautiful simplicity in elegant surroundings. It included music Maria would have loved. John Rowan, the pastor, spoke with warmth about Maria. I provided the eulogy toward the end of the service. I concluded the eulogy with an Irish prayer that Maria had spoken at her mother's funeral.

Maria had given me instructions about burial in a plot next to her father and mother. That required a long funeral procession from Sayville, Long Island to Middle Village, Queens. At the grave site, Padraic delivered the final poetic testimony. Then fifty of us went for a meal at a nearby restaurant. That part of the day had been efficiently arranged by Michael O'Brien. The food, drink, laughter, and tears flowed in abundance. Maria would have loved it, her kind of gathering.

Joan Didion points out in her book that people are always concerned about getting through the funeral. They worry about falling to pieces. But people usually do manage to hold themselves together through the funeral. The ritual is designed to support the mourners, and a tight knit community provides an emotional balance. What may catch some people by surprise is the sudden hole in the world immediately after the funeral. For the next year and more, the rest of the world goes back to its ordinary business while the mourner may still be trying to find a firm footing on the earth.

Maria's story comes to its essential close with the funeral; this memoir is her story, not mine. I will add only some details about public forums of mourning by her friends immediately afterward. I estimate that I received about four hundred letters of condolence. Some of them were brief e-mails that could be answered briefly. But most were lengthy handwritten letters. If anyone had told me a year ago that I would be faced with answering four hundred letters, I would have said I could not do it. Strangely, I did not find writing replies to be burdensome. Writing a brief note of thanks to people who expressed their deep-felt sorrow was therapeutic.

The range of letters was remarkable from people who knew her since childhood to a priest who visited her classroom for an hour in 1962 and never forgot her. I was particularly struck by a number of gay/lesbian former students for whom Maria was their chief support when homosexuality was not an open issue. I am sure she never thought of gay rights as a cause. It simply wasn't in her nature to discriminate against "outsiders." She often described herself as an outsider in institutions where she worked. That seemed odd, given that she seemed so easily accepted wherever she went. But I think she never forgot the feeling she had as an eight-year-old who was hustled off to the playground and not told that her father had just dropped dead. She seemed to have an instant rapport with people who are considered by society to be of low status. I used to sit back and marvel at this talent for talking to anybody.

Through the effort of Professor John Hull in England, ISREV established a web site. Members were invited to submit testimonies about Maria. Many of the group had already written to me. John Hull collected about two dozen of these remembrances and posted them along with a small selection of photos. Unfortunately, the digital camera had not come into general use before Maria's sickness so that photos were not as easily and clearly transferred to the Internet. I used to kid her that the best picture she ever took was one taken while she was on a whitewater raft on the Colorado River. Since she was holding on for her life, she was not posing for the camera. The result is a picture with all the wonderful emotions of her inner life evident on her face.

Two gatherings shortly after her death stand out in my mind. Fordham University's religious education department organized a memorial on March 22 (The date sticks with me because we always celebrated that date as the first time we met). Professor Gloria Durka, the most steadfast friend one can imagine, organized the program along with her colleague, Kieran Scott. Kieran delivered a beautiful tribute to Maria, based on thirty-five years of friendship with Maria and me.

I left for the memorial in plenty of time; the train ride from Grand Central is about half an hour. It is probably a reflection of my mental state at the time that I - who spends much of his life on trains - got off at the wrong stop. I showed up an hour and a half late after walking through much of the South Bronx. I felt just awful, having delayed the service, and then missing most of it. Few of the current students had known Maria except through her writing. Nonetheless, her spirit was

somehow present through the faculty that did know her. I should add that Fordham had not waited to pay tribute to her only after her death. They had honored her in December 2002, when she could still appreciate the praise lavished on her by faculty and students.

Just a few days after Fordham's tribute I went down to Hollywood, Florida, at the invitation of Joseph and Mercedes Iannone. The Iannones have for decades done superb work in education first with families and parishes, more recently at St. Thomas University in Miami. I knew that being with them would be a comfortable and comforting situation. Since Maria and I had taught at St. Thomas, many people there knew and admired her.

On Sunday evening (the eve of our wedding anniversary), the Iannones got together an intimate gathering of friends who offered remembrances of Maria. What was unusual, I recognized part way into the evening, was that everyone in the gathering had recently suffered their own loss or death. They understood the feeling of grief. Anyone in mourning can become too self-absorbed, forgetting that the world is filled with fellow mourners. This simple, poignant moment in South Florida was a fitting tribute to Maria's simple joy in the small things of life. She was a dynamo of energy for good even in her sickness and I like to believe that her presence did not end with her death.