It is over eleven years since she began to leave us. Sometimes focally, often diffusely and unconsciously, a sense of pathos colors my entire life: my prayer, my relationships, my work. And now on a Sunday afternoon in the Fall of 1995, I sit and try to make a connection, to find a place where I can be with her. My mother, recently turned eighty, sits in a wheelchair and tries to speak, to tell me about what she has been experiencing. Occasionally a decipherable word or phrase emerges, and I seize upon it, like a drowning man grabbing for a rope, and reiterate it. As I do she smiles. She seems pleased at our communication and encouraged to say more. But in the spaces between my exhausting efforts to hear and find responses, I miss her. As I reflect later that evening, “You never miss someone as much as when you’re with them, but they are not there.”

From the early months and years of this disease, characterized by the inexorable unraveling of all that lends familiarity and coherence to daily experience – the loss of keys, the forgetting to pay monthly bills, the inability to remember the way back to one’s car or the way home, the spoiling food and the unwashed dishes, up to the final years and months in the Alzheimer’s unit of the nursing home and the loss of speech, the increasing instability, incontinence, and final immobility, loss of consciousness, and death – I find myself, as Ignatieff’s narrator, struggling to find “... some way to redeem this, some way to believe that the banal heartlessness of it all ... [is] not for nothing.” (Michael Ignatieff, Scar Tissue, [New York, Farrar, Strauss and Giroux, 1994], p. 1 All further references are to this edition).

In the earliest year, I, as the father in the novel who copes with his wife’s disease by “relentless tinkering” (p. 19), find redemption in the effort to hold together life as familiar while spending hours a day caring for my mother. I scurry and strain to keep things, which she is constantly displacing, in place, to clean her apartment, to pay her bills, to send out her Christmas cards, to see to her meals. Then, as she is increasingly unable to be alone, I try to find a way to keep her with me more and more. I create work for her to do around my house and office while I am working. I take her with me to meetings, on errands, and on visits to friends. When more help is needed, I finally submit to sending her to adult day care and, after much resistance, bring in home health aids to take over some of my responsibilities. It is not easy to give aspects of her care over to “strangers.” But after a while we settle into a new routine, and a different but reassuring sense of “normalcy” returns.

One cold, rainy November morning, however, this newly established order comes crashing down. At 7:20 A.M. I receive a call from Lee, the home health aid who goes to my mother’s apartment each morning to prepare her breakfast, dress her and get her off to day care. She tells me that when she got there she discovered my mother, dressed only with a light raincoat over her nightgown, wandering in the parking
lot outside of her apartment building. The delicate balance between maintaining a separate life and caring for my mother, which I had spent the past six or seven years trying to maintain, was broken. She could no longer be alone, even for what had been the sleeping hours of night. Short of living with her twenty-four hours a day, there was no more that I could do. I had reached the limits of my own efforts to keep, even a semblance of life as it was.

From my earliest years my mother had taught me the conviction that hard work could overcome any obstacle. But both she and I were now being taught the lesson of the book of Job. Who are we to say what is the way things should be? Where were we when God created the world? One evening, not long afterwards, she and I are sitting together on the couch shortly before her bedtime. She is, as often after dark, feeling very anxious and fearful but is able tonight to verbalize her feelings. As we speak about her experience, and that of her oldest sister who is also suffering from this disease and has now been in a nursing home for two years, she recognizes the limits of her efforts and mine. Much to my amazement, she says to me, "Do you think I could go to a nursing home? I think I may need that soon."

Throughout her life this person’s courage and strength had been apparent. In her setting out on her own at the age of sixteen, through the deaths of her first born child and first husband, to her accomplishments in the business world and her holding together of our family through several years of my father’s unemployment, she had always demonstrated a powerful ego and will. But now I am touched to the core by an even greater potency. After all the work and effort to create a life for herself and her family, she is able to recognize and acknowledge the limits of those efforts. The time has come to depend on others to do what we can’t.

On the first week of New Year 1992, I leave my mother at a nursing home. By the time we finish lunch together in her room, it is clear that, for the moment at least, she is aware that this is where she is to stay. She turns to me and tells me that I must be busy and I can go now. Typically for her, she lets me go – even if I am not ready to release her. As the narrator of Ignatieff’s novel says to a nurse at his mother’s nursing home, “I’m going to stay ... not because I have to .... Because I need to.” (p. 112)

That evening I write in my own journal:

I miss her. I worry about her. I love her. I am grateful for her and who she is. I am grateful for the tears that have not always been able to flow. The sadness, the loss, the lack is more profound than I ever knew. And I’m sure I still do not know it. I pray that she is okay, and that in her loss she may also know the Love. Dear God, hold her in your aims. I love you, Mom; I forgive you; Ill try to let you go. Please love me and forgive me. That God may love and forgive us. Amen.

What is it that the narrator needs from his mother? What is it that I need? In his dialogue with the nurse Miranda the following interchange occurs:

“You want to hold on to her as long as you can.” “Yes, I do.”
“You want her to help you.” (p. 111)

What is the help that he and I want? The answer, of course, is complex and mysterious. One aspect of the answer is that I need her and her living out of her illness to teach me, to form me, to reform me. As the narrator reflects:

“Sometimes at night, lying by her side, I think about all the memory that must remain inside her, trapped within the circuits, denied speech yet present in her mind. She is the silent custodian of the shadow zone in my life.” (p. 50)
I need the relationship to continue because there is so much I do not yet know about her, about me, about who we are in relationship to each other. I hold on because I still need her help if I am to learn to love her, to forgive her, and so to let her go.

I sometimes imagine, and perhaps wish, that the pain of this relating and learning and being reformed will come to an end. Thoughts of receiving the call informing me of her death or of discovering her physically unwell when I visit often pass through my mind. I can wish (for her? for me?) that some night as she rests she will just stop breathing, that her (and my) suffering will end. But for now, abandonment to Reality, to the will of God means for both of us to carry on, to live out the moment-to-moment, day-to-day experience of this illness.

After several months of her adapting well to nursing home life and so giving herself and me a restored sense of routine and order, my mother enters a new and yet more frightening stage of her illness. The taken-for-granted is once again disrupted. One night, shortly before bedtime, I receive a call from the nursing home. My mother has attempted to suffocate another patient with a pillow. The next day she is transferred to the psychiatric unit of the local hospital. I am frightened and horrified by this turn of events. How can this be? Who is this person? What shall I encounter when I get to the hospital to see her?

At this moment I experience the emergence of my worst childhood nightmares. The one whom I have always counted on as the seat of strength, stability, and responsibility in the vicissitudes of our family’s life can no longer check and channel her own reservoirs of fear, anxiety, and rage. The powerful forces of the “underworld,” long-feared and strenuously contained, have finally and overwhelmingly erupted. I am enraged at my mother, at the nursing home, at those in the hospital who restrain and drug her, and at God, whose presence and activity I do not, at this moment, recognize. But most of all I am afraid, both for her and for myself. Is this illness to take not only her health, her life, her presence from me, but also the means she gave me of “getting through” life, of dealing with its darkness?

My mother, through word and example had taught me to pay no attention to the pain, loss, and weakness of life. “It’s not good to dwell on sad things. There’s nothing you can do about them.” So you choose to turn away from illness, weakness, loneliness, addiction, death as aberrant and work at making things better where you can. In my home one laughed and worked and played as if nothing was ever wrong, even when it desperately was. And now, in the middle of my life and at the end of my mother’s, it has become impossible to avoid the sadness and the madness that are part of our journey.

I realize, of course, that violent behaviors and extreme personality changes are “a part of this disease.” But “reality” for me has always been, in part, the world my parents described and gave to me. And in that world, there may be rage, grief, despair, hatred, and violence, but it could always be kept at a distance through sufficient effort, care, love, and humor – and when all else failed, denial. And now that world is gone. As I continue to stay with my mother as she falls deeper and deeper into the darkness of this illness, I cannot say “This isn’t her.” For it surely is. She not only now rages and strikes at those who frighten or crowd her, but she continues to affectionately hug and kiss and thank those who greet her and help her. She not only jealously protects her own space, but she caringly offers to share the cookies and candy we bring her. This person, at once familiar and strange to me, truly is my mother.

Step by inexorable step many of our most hidden fears, my mother’s and mine, have become realized. We have spent life trying to find, if not create, redemption. We have tried to redeem ourselves by earning recognition and respect and by promising to protect each other from the darkness of our own pains and lacks and fears. And all that time we were fighting the anxiety which kept reminding us of the futility of our efforts. Now her days of working and earning and protecting are over. There is only the call to “go through” the mysterious and awe-full progression of this fatal illness. And for me, there is no way to
protect her, or myself, from going through what is asked. Is this the way we are to be delivered from ourselves into the realm of pure obedience?

The narrator of *Scar Tissue* is brought by his brother, a neurologist, to see a patient of his, Moe, who has been bedridden for five years with ALS, motor neuron disease. He is able to communicate only by means of a breath controlled computer. Each use of the computer to communicate costs him such effort that it lessens, perhaps, the ultimate duration of his life. The narrator tells him that his father had said that their mother was “on a journey away from us.” Although none of them could have any idea of what that journey was like, he thinks Moe can tell him something about it. Moe struggles for several minutes to bring up words "from deep in the shaft of sickness." And he writes:

a journey, yes  
away from my body away from family and the world I know  
into the heart of life (p. 141).

As I try to accompany my mother on this journey, I realize that there is nothing I can do but try to stay with her. There is no longer anything to say or do that can protect her, or pretend, or deny. There is nothing left but to be with and go through. Every moment I spend with her in the Alzheimer’s unit breaks apart every presupposition and preconceived understanding about what is necessary and valuable in life. There is no longer any significance to “Why?” questions. The truth at this moment is simply the way things are. Yet, when I am just simply present to her and with her, I (and I hope and pray she) experience more than occasionally what Moe speaks of:

I lie here; I cannot move; however, I can listen, think, pray.  
How is it I feel love? and where is it coming from? (p.137)