



MINERVA RISING

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Relationships & Desire



The Promise

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DECEMBER 25, 2000

It was the first Christmas of the new millennium. Instead of celebrating the holiday on that cold winter morning, I was with my family at Barnes Hospital in St. Louis waiting for my father to die. Having grown up as Orthodox Jewish immigrant, he'd always hated Christmas. He said it made him feel like a pariah that everyone around him was celebrating with family and friends when he wasn't allowed to. Dying on that particular day pretty much guaranteed that the holiday would never be a happy one for any of us, ever again. He'd always been a man who was used to getting his way so that fact would actually have been quite satisfying to him.

He'd had leukemia for about a year and had endured two difficult rounds of chemotherapy. We'd enjoyed a wonderful Thanksgiving together while he was in remission only six weeks prior, but the cancer returned with a vengeance and quickly began to engulf him. This day had been expected and we decided not to pursue any further treatment. One of my brothers is a doctor and led the decision-making so it all seemed very rational. Except that it wasn't.

My father was taking a really long time to die. Finally, the nurse stopped my brother and me in the hallway and said, "I think he's actively, resisting dying. He seems worried about something and can't let go." My brother,

my stepmother, and I walked into his room and, indeed, he did appear to be fighting. Not fighting death so much as fighting to communicate something to us.

I noticed that his eyes kept moving around the room — darting back and forth between me and my brother — but focusing mostly on my stepmother Marilyn. At that moment, it struck me what the problem was: he was worried about her.

His worry was not without reason. Marilyn and my father had been married for 25 years. She met him long after he and my mother had been divorced, so she had nothing at all to do with the atomic bomb that hit my parents' marriage.

Nonetheless we, children, even as young adults, were terrible to her. Really terrible. It was the mid-1970's and divorce was still relatively uncommon, so my parents ended their union in an uninformed, spectacularly bad way. The family was a mess and Marilyn, unsuspectingly, walked into the snake pit.

It only made matters worse that Marilyn was a little odd. She was an art historian of Ethiopian Christian Art of the 14th and 15th Centuries. To say that this niche area of study was her vocation would be an understatement. It was her obsession. Here was this tiny a-religious silver-haired white woman who had a consuming passion for centuries-old Ethiopian Christian texts. She talked about

them energetically and endlessly. In great detail. All of the time. Hers was an intellectual passion taken to extremes.

Her inexhaustible discourse about Ethiopian art of the Solomonic Era didn't bother my father because he never really listened to her. He liked her quirkiness. She was a cheerful, willing, companion to him and because he didn't listen to what many people said to him anyway, it was a perfect match.

On the other hand, she drove us kids nuts with her never-ending tales of Emperor Zara Yaeqob, the Cult of Mary, and the Abba Garima Gospels. We shut her out. Entirely. We ignored her to such an extent we simply pretended she didn't exist. We totally obliterated her.

So, my father's desperate worry about Marilyn on that fateful Christmas morning was not without foundation. He and Marilyn had had no children of their own together and her family-of-origin had long ago expressed their disinterest in her and her Ethiopic preoccupations. After a quarter century of a happy marriage, he was just plain panicked that she would be alone and lonely for the rest of her life. And he desperately didn't want that for her.

In watching his eyes dart back and forth from her to us and back again, and wanting to find some way to appease his anguish, I took his hand and said, "Don't worry, Dad, I'll take care of Marilyn." He looked at me, visibly relaxed, and then he died. And that was the beginning of "The Promise."

JANUARY 2001

For the first few years "The Promise" was easy to keep. Marilyn continued to live in St. Louis and my family was growing and our lives were busy with the children's schools, Hebrew lessons, piano recitals, sports

teams, and my own work making documentary films and teaching my students.

Even with all of that activity and time passage, Marilyn was in mourning and so was I. As difficult a man as my father was, he was the emotional core of our family. I took solace in Marilyn's sorrow. I valued her devotion to my father and she had a somewhat wary appreciation of me. I understood her caution, I had been one of her obliterations. But she was sad and needful and so was I. We consoled each other in a civilized, but slightly distant, way.

One of the good things about Marilyn is that she liked to travel. She would arrive in suburban Washington DC where my family lived at a time when my own mother literally never left her house. Relatively quickly, Marilyn increasingly became an active part of our family calendar.

Within a couple of years it became clear that Marilyn had no idea why she was continuing to live in St. Louis. The small group of scholars who studied in Marilyn's world was elsewhere. I suggested that she seek support for her academic work so she could move her life forward. She applied for a fellowship at the Metropolitan Museum of Art in New York City, which she won. And then she applied for another one at Dumbarton Oaks (Harvard's Center for Byzantine Studies) in Washington, D.C. and she got that one too. Once she had decamped from St. Louis for two academic terms, it became clear that there was no conceivable reason to return.

So, in keeping with "The Promise" and in the spirit of shared familial love, I cheerfully suggested "Why don't you move to Washington DC permanently? We can find you a place to live, you can be with the kids more, and just think of all of those museums and scholarly conferences on the East Coast! After several years of having floundered since

my father's death, she readily agreed.

JUNE 2, 2005

Silver Spring, MD is the small suburb next to our town and it was undergoing a renaissance after decades of blight and commercial decay. But in what has to be the oddest twist of fate, Silver Spring was rapidly becoming home to largest population of Ethiopians outside of Addis Ababa. There were groceries, small businesses, and restaurants all owned and operated by Ethiopian immigrants sprouting up one after another. We found a condo for Marilyn in the midst of this Ethiopian Diaspora – it was kismet!

Other than her predilection for art of the African Continent, I actually knew very little about Marilyn except what she wanted us to know. After all, my only connection was with her as my father's wife – one he had come to marry after I had already grown up and left home. Her financial affairs, her future plans, her private decisions about how she would govern her life were all hers to make. None of it was my business. And I was totally fine with that arrangement.

Marilyn moved to the DC suburbs and life continued apace. She regularly traveled to Ethiopia for her scholarly research and she engrained herself in the Ethiopian community that surrounded her. She made lots of Ethiopian and Ethio-centric friends and she became a consistent presence in our home – for holidays, birthdays, graduations, and most of all for “Sunday Dinner,” a meal that I made weekly with religious regularity. It felt good to all of us.

JULY 22, 2011

Marilyn had a car accident. She was making a left turn out of her driveway and she said she hadn't seen how fast the car was coming. She had never liked driving in DC. She hated the traffic circles and the diagonal streets so I didn't think too much about this particular accident.

Marilyn blamed the car, not herself. And then began what I came to refer to as the “Dance of the Automobiles.” Over the next few years, she would buy a car, try it out, she would say she “didn't feel comfortable in it,” we would trade the car in, buy another car, and the cycle would repeat itself all over again. In hindsight, it was pretty crazy. But at the time it seemed no crazier than her obsession with Ethiopia so it just seemed all of a piece to me.

FEBRUARY 2013

Marilyn began to complain about her eyes. She had surgery that got rid of her cataracts, but not the complaints. She said she was having trouble reading through the complete lines of ancient text in Amharic. From my perspective, that didn't seem like a big problem, but it was a huge deal to her.

So, we began the “Dance of the Eyeglasses.” We spent hours at the pharmacy trying on reading glasses, buying different pairs, eventually discarding one after the other. Then there were umpteen visits to the eye doctor. I decided this was part of the fulfillment of “The Promise” so I went along with it even though I found it increasingly annoying that I was becoming so close to her physicians. And naturally it did start to make me wonder who was going to take care of her if her situation deteriorated for some reason. But I put it all out of my mind, confident in

the knowledge that she had a family back in St. Louis who would step up in the event of a crisis.

Better still, things seemed relatively normal – she continued to travel to Ethiopia and went north of Addis Ababa to visit the remote monasteries in Mekele. She gave papers at Oxford and at the University of Berlin. She was curating an exhibition and editing a catalogue on Ethiopian iconography for the Museum of African Art at the Smithsonian Institution. I didn't understand a lot of what she was doing, but her work was definitely "hot."

NOVEMBER 16, 2015

Marilyn's regular eye doctor had begun to get that furrowed brow that physicians get when they don't know what's going on. And that led to many referrals – and more doctors – and more tests – and more furrowed brows. Until the day when we walked into the office of one of these increasingly hybridized specialists and within minutes of examining her he asked her to leave the room to check in with the nurse. I thought, "Uh oh, this can't be good." It wasn't.

He said that he had only seen a few cases of her diagnosis in his career - and he wasn't a young man. She had "Benson's Syndrome" also known as "Post-Cortical Atrophy," which he described as a rare form of Alzheimer's. The increasing problems of her vision, her inability to gauge the speed of the car that hit her, her difficulty in tracking lines of Ethiopian text - all of which we had simply attributed to age – were, in fact, the creeping atrophy of her senses.

The doctor told me that she would eventually go blind, and maybe deaf, and then the disease would slowly progress towards the front of her brain and she would ex-

hibit the more classic symptoms of Alzheimer's of memory loss and declining cognitive brain function - but that this could take a very long time. And worse, in the midst of it all, she would probably develop delusions that would come to terrorize her.

"Oh my God," I thought to myself, "This is waaaaay more than ever I bargained for." Both of my parents had died relatively uncomplicated deaths due to explicable medical conditions. This was entirely new terrain for me.

I immediately contacted her family back in St. Louis with all of this new information. All I got back was stone, hard, silence. Oh no.

Now I felt locked into "The Promise" and there was no way out. It felt like entering the abyss.

SEPTEMBER 2016

In deference to my panicked confusion and Marilyn's proclivity for denial, for a while we pretended nothing was wrong. I helped her as much as she would allow and that seemed enough. She had become a big part of our lives to be sure, especially as the doting grandmother that my children never really had.

But our own relationship had never felt like a natural fit. We didn't know who or what we were to each other. She wasn't my mother and I wasn't her daughter. Ours was a contrived match made of need and the mutual love for a man who had now been dead for 16 years. It wasn't a relationship of blood, or choice, or emotion. We didn't know exactly what it was so we simply avoided any conversation about the truth of our circumstance, and its implications, altogether.

Our mutual denial was abetted by the fact that being as independent as she was, she vehemently didn't want

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help. We focused on particular details as she would allow: if we planned her daily activities she was fine on her own, living in her small apartment within walking distance of the pharmacy, the grocery store, and all of her Ethiopians. And this strategy worked out fairly well, for a while.

Eventually this more casual arrangement became too challenging for her eyesight. Thus, we began the “Dance of the Caregivers.” I contracted with an agency that sent in helpers known as “Angels.” These were very nice people whom Marilyn treated very badly. She was angry and she called these people “stupid” because they didn’t have a PhD as she did. But now they were helping her read and type and do her daily chores. She hated every single one of them. We went through quite a few “Angels” before this particular “Dance” was over.

But most of all she was extraordinarily angry with me. I was a constant daily reminder of everything she couldn’t do or be anymore. She resented me and had always been somewhat wary of me to begin with. Ironically though, she was also dependent upon me, so she couldn’t hate me 100%. But it was pretty close to it – maybe about 85% hate. We were both locked into “The Promise.” Me hating my inextricable circumstance and her hating me.

DECEMBER 21, 2016

Then one day her neurologist said that Marilyn needed even more regular help. No more cooking, or walking the neighborhood on her own, no more bathing or dressing alone, no more managing her finances, etc. etc. etc. I could take responsibility for some things, but

her activities of daily living meant hiring full-time help— a process to which Marilyn REALLY OBJECTED.

I called every agency I could find and led with the question, “Do you have any Ethiopian caregivers available for full-time work?” Soon I found “Etsi.” Really Etsegenet, but Etsi to us.

The first day Etsi arrived, Marilyn wouldn’t go near her. We stood in the kitchen and I began to tell Etsi about Marilyn’s work in Ethiopian Christian Art, about her many trips to Ethiopia, about her ability to speak Amharic. Etsi was incredulous. Eventually, Marilyn sidled over and said, “Would you like to see the book I wrote on Ethiopian Christian Art?” And out came African Zion: The Sacred Art of Ethiopia. The two of them began to pore over it – Etsi, being a good Ethiopian Christian, and Marilyn, having incredible recall of every part of the Abu Gharmi Gospels (her disease not yet having affected her long-term memory) they were enraptured with each other.

Soon Etsi and Marilyn had built their own world. They would eat Ethiopian food together, they would go to Etsi’s church where the priest would wash Marilyn’s feet because she was so revered, they would welcome many Ethiopian scholars and friends into Marilyn’s apartment. All the while, Etsi would bathe her and teach her to use the “senior toilet” and convinced her to use her most hated walker. The loop was closed. I was no longer necessary. With a wonderful full-time Ethiopian caregiver Marilyn could hate me all the time – 100% hate. But it wasn’t so bad because Etsi was our buffer.

DECEMBER 6, 2017

U ntil one day. Marilyn’s neurological evaluation came back even more dire. I had noticed the

decline but hadn’t really dared to think about “what next.” She was now totally blind, she was losing all of her recent memory and most of her executive functioning and cognition. She could no longer be alone at all any more, which meant 24/7 care by multiple caregivers.

I found a wonderful facility near our home. The doctor told Marilyn that she was going to Arden Court to “get stronger.” One thing I’d never done in all my years of caring for Marilyn, no matter how strained our relationship could be, was lie to her. And certainly I would never have told her such an egregious lie. I was both grateful to the doctor that I didn’t have to actually utter those words, but was still tormented by the fact of our conspiracy against her.

Everyone knew that she would never be able to leave Arden Court. And Marilyn was still relatively cogent enough to know the same. So she was mad. Madder than she’d ever been at anybody, probably ever in her whole life. We arrived for the first day at Arden Court and she began to blow fire. It was all directed at me - I was the enemy who had taken away her beloved Etsi, her apartment, and every aspect of her independence. I was now 150% hated, as if such a level of hate was even possible.

JUNE 12, 2018

J une 12 is Marilyn’s birthday. For six months Marilyn had maintained the consistent drum beat of vilifying me – railing to everyone and anyone she could find, yelling, screaming all kinds of obscenities about me. Unable to see or reason by this point, the tirade would happen at all hours of the day and night. She was as violent as a small, blind, white-haired lady in a wheelchair could be.

While the staff at Arden Court had never cared for a Benson's Syndrome patient, given its rarity, they had cared for many angry Alzheimer's patients. Inch-by-inch they helped Marilyn acclimate. She didn't want to participate in group activities but she was willing to sit in her wheelchair outside the room, peering in. She didn't like certain people whom she thought were attacking her - a belief that became more profound as the delusions deepened - so they "separated her" from these threatening beings. They played Ethiopian music in her room and not surprisingly given the demographic make-up of our region, some of the caregivers were Ethiopian. They brought Ethiopian coffee and injera for her "special meals."

We decided that it was best not to provoke her, so I stayed away. I couldn't imagine how this would resolve itself. Now, on top of feeling locked into "The Promise," I felt guilty and horrible and responsible for her misery. Everyone kept telling me to "be patient." I'm not a patient person, so I had a hard time imagining what those words even meant in this context.

Then six months in, on her birthday, something happened - we don't know what exactly. But I got a call telling me that Marilyn was asking for me. I responded, "I'll be right there." I stopped on the way to buy a cake for her birthday and I walked in and said, "Marilyn, it's Nina. Happy Birthday. Here's some cake!" And she said, "Nina, where have you been? I'm glad to see you!"

Of course, she couldn't see anything at all, but I understood what she meant - the rare form of Alzheimer's that had sent her to this place had finally progressed enough to make her forget that she hated me. I suppose that's what everyone meant when they said, "be patient."

Now, all she wanted was me. She asked for me con-

stantly, all of the time. I visited often. I got close with her caregivers. I came to know the other people on her hallway. I fed her crackers and pudding and juice at snack time and the regularity of my visits made her happy, or at least as happy as someone could be in her condition.

But the more she asked for me the guiltier I felt that I couldn't visit every day. I came to feel that nothing I was doing was ever enough. Inside of the promise I'd made to my father, I was caught in the endless cycle of her growing desperation and deepening insanity. I felt like I was drowning.

NOVEMBER 1, 2018

Early one morning I got a call that it was time for Marilyn to be considered for hospice. It hadn't been that long since she'd forgotten that she hated me and even though she was declining, I thought, once in hospice, hers would be a relatively quick, peaceful path towards the end. Alzheimer's is always said to be "the long goodbye" so it's easy to lose track of time. Nonetheless, this appeared to be a big step towards the end.

But months went by and her disease simply got worse. She could no longer eat, so she got nourishment through a sponge dipped in fluids. She was skeletal. She no longer had conscious body movements so her body flailed and heaved in all kinds of odd ways. She would randomly vocalize, quite loudly, with peculiar animal sounds. I thought to myself, "this is inhumane, unmerciful, no one should ever be subjected to this. She needs to die." And then I felt guilty that I even felt such a sentiment.

Eventually, she no longer knew who I was, nor anyone else she had ever known, including my father. One day I asked her if she remembered her trips to Ethiopia. And she

said, “What’s Ethiopia?” That was the day that I cracked.

I had told Ann, Arden Court’s Director, about “The Promise” when Marilyn was admitted to the facility, it being such an oddity that a stepdaughter would be taking such personal, intimate daily care of her stepmother. On the day Marilyn could no longer remember Ethiopia and I fell apart, she said, “Nina, you have fulfilled the promise to your father. We can take care of Marilyn, but we can’t take care of you.” Ann is a wise woman. Because we hadn’t hit rock bottom yet.

Every time I thought the situation couldn’t get worse, it somehow did. The nightmare kept expanding. Marilyn was still very much indomitably alive and somehow even more emaciated, but still strong enough to be thrashing around and hollering incoherently at the top of her lungs all the time. I didn’t know how her caretakers withstood it. But they did. I would go see her, sit with her, try to comfort her without avail, and it would kill me.

Ann was right, they couldn’t take care of me, nor could anyone else. I felt entirely at sea, lost in the vastness of “The Promise” that I had made to the father I loved. In spite of all rational knowledge to the contrary, it seemed that the torment would never end for either of us. Marilyn and I were joined in “The Promise,” both of us caught in our own endless spiral of desperation.

JULY 15, 2019

Marilyn died. I got the call a day before that she was “declining,” which I suppose is a euphemism for “actively dying” or they wouldn’t have called me

at all. By that point she’d been “declining” for years and in hospice for nine months, so this was a foregone conclusion.

The nurse told me I didn’t have to come to see her. I appreciated her consideration of all we’d been through and how I might not be able to take one more minute of it. But, of course, I went anyway.

Marilyn was finally quiet. She wasn’t screaming or hollering or thrashing. I held her hand. I told her that we all loved her and it was time to let go. She didn’t move. She didn’t seem alive but she was. Perhaps I was getting through to her. Perhaps I wasn’t. It didn’t matter. I was going to take care of her up until the end. The next day she died.

It was finally over. I was totally exhausted and entirely relieved. None of us could possibly have imagined the journey those two words that I had uttered to my father 18 years and 202 days earlier would have sent me on.

People kept saying to me, “Oh you’re so wonderful for having taken care of her.” I didn’t see it that way. Being “nice” or “wonderful” implies a choice that is being made – to either do something or not. I had no sense of volition. I had no feeling of agency over my actions. I felt bound by what was required in “The Promise” and its exigencies as they revealed themselves over time. But most of all, what I really didn’t want was to break the fundamental bond with the man who had left me behind nearly two decades ago.

“I Promise.” Those can be very tough words to live by. 