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STILL THE END:

THE CHRONIC LIFE AND TIMES OF A WELL SPOUSE

MARION DEUTSCHE COHEN

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CHAPTER I: LESS DIRTY DETAILS

From 1993 to 2003 my husband Jeff had a suction tube a few feet from his bed in the nursing home. He asked increasingly for it. At first he'd mutter his usual brand of denial: "I don't really need it. It's just for security." Later he stopped saying that.

"Asking for it" meant asking me to take it off the hook and put it in his mouth -- just close enough to his throat to get at what needed to be suctioned out, but not close enough to choke him. Little bits of greenery and brown-ery, failing to dissolve in saliva, floated down that transparent cylinder. They collected at the bottom, a slimy ocean to imagine bathing in. In other words, yuk.

In the fall of 1993 I tried to write a poem about it. But as some poets say, "there has to be a distance". And it would be a very long time before there was that distance.

Our seven-year-old Devin was, at the time, home-schooling, and still not reading or writing. I wasn't worried about this. I knew that often home-schoolers don't read at the same early age that school kids do. And I knew that, when Devin was ready, his brain would learn. Or it already had learned and he just wasn't letting on. He was a writer, though; I could tell that. He'd dictate his stories to me and, though they were full of abrupt changes in scene and telling rather than showing, I detected creativity -- about as well as within them. For example, at one point he dictated, "Do you want to know what he looked like? His picture is on the next page."

“Why not this page?” I asked.

“Cause they’re not supposed to see him right away.”

In one story a man’s parents were killed as soon as he was born, by the doctor “who took him out”. Why? “The doctor wanted him to be lonely.” Why? “I don’t know.”

Writing fiction is something I seldom do. I can’t bear to make sad things happen. I can write about sad things that have already happened, but making them happen? -- I haven’t the heart. Devin, though, did. He could make bad guys, weapons, killing, as much as he needed to. And apparently he did.

This chapter is called “Less Dirty Details” because the details are less dirty than before Jeff went to live in the nursing home. Suction tubes are nowhere near as dirty as “nights, lifting, and toilet”, the quick phrase I used to describe the former details. Nor as the shit I used to wipe, sometimes merely off him but other times off the floor, mattress, his thick jeans. Nor as being awakened thirty times a night whenever Jeff needed to scratch an itch, still a spasm, turn over, pee -- or shit.

Now, only at the nursing home were the details of my life even slightly dirty. At home nights were for sleeping, toilets for *my* shit, and liftings non-existent. Sure, I lugged huge bags from the thrift stores and years later I’d lift my grandchildren. But never again would I lift a man weighing more than me onto the toilet or up off the floor.

Oh, I WATCHED lifting, watched the aides do it; three at a time did what I’d once done single-handedly. Part of me would, not exactly gloat, only be grateful. This book is about stress, not dire straits. But there was enough stress for a book, and for a life.

Other well spouses know what I mean. The rapport we all had and still have is amazing, life-saving, often just-plain fun. One evening, for example, I was on the phone with Fern, whom I'd met several years before at the first Well Spouse Conference. We knew we might be interrupted by her Jim calling "toilet". We were talking about furniture. "Ya know, Marion, there are so many little *subtle* things, like if there's a particular rug that he likes and you want to get rid of --"

"Oh," I interrupted, "I *am* re-doing the living room." We laughed heartily. Then she told me about the new curtains she'd ordered. "Has Jim seen them yet?" I asked.

"No, not yet."

"Right," I laughed. "'Cause they're not *his* curtains."

"That's right, they're not." Again we laughed together, seriously -- about our desperate need for and determination to have curtains, rugs, fun, and normalcy. Both of us understood that a well spouse can never get enough perks.

Fern and I sometimes exchanged dreams. I especially remember the one about Jim's funeral; in the dream she got sidetracked in preparing it and instead took a young lover. Everybody-but-everybody was furious at her for this, and I told her that I wasn't.

"You WILL be going through difficult times," said Roberta, my friend and publisher. She had put out "Counting to Zero", my book of miscarriage poems, and now "Epsilon Country" was forthcoming, the second in my trilogy of well spouse poems.

"Oh, I *am* going through difficult times," I answered. "But it's nothing compared to the 'difficult' times before he went into the nursing home." Soon I also had a dream about

taking a young lover. When I woke up I remembered his phone number; it was 215-939-2840. What if I had tried dialing it? “I hope that, when you’re ready, you’ll start dating,” said my friend, writer Rachel Simon.

“Yes, I’ve given myself permission to date, when I’m ready,” I answered. “But I’m not ready.” No, not ready at all. I felt I’d had enough sex in my life. More than enough, in particular more than enough of what I called “disability sex”. Also, of adult things, ultra-adult responsibility. I didn’t want more. I wanted to be taken care of and loved in non-adult, non-sex ways. Besides, I still loved Jeff or thought I might. The idea of a new man scared me. If I didn’t date, would people think I wasn’t adjusting, wasn’t moving on, wasn’t paying attention to my own life? I knew that I was.

I told Fern another dream: I’m caregiving a friend who has a bad cold. It’s regular caregiving. I do things like make up her room and bring chicken soup. Sometimes I hear her tiptoeing about. There’s no lifting, no toilet, certainly no nights. In fact, she sleeps ‘til noon so not even mornings.

Around October of 1993 my home-schooling and writer friend Nancy Wallace said to me, “It *is* the end of your marriage, as you know it.”

“Yes I know” I answered.. “But that’s not what I’m feeling just yet.” No, I wasn’t ready to feel that. Still, in November of 1993 at the Well Spouse weekend, I watched the flirter. “Could that be me if I wanted?” I wondered. I thought of thirty years ago, back in high school, how long it had been before I’d gotten asked out on a date. “But I’m different now,” I thought. “I’m more experienced. I’ve had five babies, for Chrissake. I could do it if I wanted to. I know I could.” I had to keep reminding myself of things like that.

Jeff didn't seem terribly interested in his family. When I hugged him he didn't respond, not even flexing which he did, back then, have enough movement for. The questions he asked me were usually very general. "How is such-and-such?" And he didn't say much to Devin. Also, Devin didn't hug him.

And Jeff seemed tired. He'd been through so much, for such a long time. Fern and I had been talking about shock. That's what her Jim had called it. Jim and Jeff were probably both still in shock -- about their whole situations, however long-lasting and gradual they had been. Jeff had hoped to finally be promoted to full professor, after over a hundred important physics papers. Instead he'd gotten disability benefits and nursing home. Every morning, he once told me, he'd wake up and be, yes, shocked to find that he couldn't move. He'd expect to stretch, turn over, reach for me, get up.

In the face of illness the ill person often has meddling friends. Other well spouses had talked about that. While Jeff still lived at home two friends were getting him all riled up about "the night nurse". That, I knew, had been a ploy to avoid nursing home; if I didn't have to get up at night, they figured, I wouldn't need Jeff to live away from home. They hadn't thought about the shitty sheets in the laundry, or the "night nurse" we'd once actually had who, more times than not, hadn't shown -- also, insurance never pays for custodial care. When I reminded them, they stopped the "night nurse" shenanigans.

But those two friends had not disappeared. They visited Jeff in the nursing home; one evening one of them phoned me with something he wanted me to worry about. He began slowly. "I visited Jeff last Sunday, and I'm concerned that there's still trouble with the suction tube. I think Jeff might be being intimidated into not asking for it..."

“Jeff?! Intimidated?!” was my immediate unspoken reaction. What I spoke was “I’m sorry, I don’t have time to listen right now; my tax accountant is here. Thank you for alerting me, though.”

“Well, you haven’t let me *finish* alerting you,” he answered.

“I’m sorry,” I said, and hung up. I had just come back from visiting Jeff and he hadn’t complained about anything -- and I had indeed asked. Why didn’t this guy get his own family to worry about, or at least a part-time job?

At our daughter Marielle’s wedding just a month before, she and Matt had stood at that little indoor window of The Restaurant School and, looking adorable, made ready to throw the bouquet. Rosemary, Matt’s “grande old aunt”, turned to me and quipped, “Well, I’ve been a widow for 17 years; let her throw it to *me*.”

“Yes,” I quipped back, “You need it more than I do.” Then I yelled up to Elle and Matt, “Throw it to Rosemary! Throw it to Rosemary!” A few other people joined in, “Throw it to Rosemary!” So Elle threw it to Rosemary and Rosemary caught it. “Yay!” we shouted. Rosemary and I hugged and laughed. A few minutes later she turned to me and said, seriously, “I want to give it to *you*.”

“Oh, no,” I answered. “I want *you* to have it.” But she insisted, taking my hands and placing the bouquet in them. So I said, “This way it’ll be like we both have it,” and we hugged some more. Then, though, she told me, “The bouquet is so your husband gets better.” That had not been what I’d had in mind. Things had gone too far for him to get better, and for that to make a difference if he did.

A few nights later I dreamt about what I'd had in mind. I was at some lecture and the man in front of me, young and good-looking, said to me, "There's this girl I like. What do I do?" I knew he was talking about me. I gestured for us to leave the room and then began telling him about my situation. "I'm not ready to start dating yet, but when I am I'll know it and you'll know it and then, if you still want to ask me out..."

But I hadn't gotten very far in my explanation when he interrupted me. "What nursing home is he in? How can you afford to pay for it? How's he doing?" In other words, he changed the subject, from me to Jeff. He acted like a lot of people in real life.

We were waiting for a bed to open up at Inglis House. Right now, temporarily, Jeff was at a place rather fancy in decor -- pastel furnishings, private bath -- but it was not the place for him. It did the best it could, but it was an old age home; they weren't used to suction tubes and call bells. So they didn't answer Jeff's, or not very quickly; sometimes he would wait for hours, or so Jeff said. He would wait in shit, or so he said.

Denise insulted him. Then one of the good nurses told him not to complain, Denise would have it in for him if he did. "Do you want your breakfast or not?" Denise would snap, or so he said. She then added, "I can't stand the smell of that green sauce", referring to the Indian spices Jeff would have put on his food. "If you have it again," Denise continued, "I'm not coming in here any more." The good nurse would say, "Denise uses every excuse she can find to run off." Or so Jeff said. Who to believe? What to do?

Jeff told us that they answered his buzzer right away only while we were visiting. They never had time for him; they would forget about him. He hadn't been outside, or

out of bed, in a week. It just didn't seem as though they were doing their best to make him comfortable. Or so, again, Jeff said.

"Don't you dare forget about him," I told them. "He's a physicist, a husband, and a father." But they didn't have strong men available on a regular basis.

I *can't* take him home, I would think frantically. I just CAN'T. No one, not even Jeff, ever mentioned that but I was still worried. I *couldn't* go back to nights, lifting, and toilet. Friends were saying, "You look so much better." No, I couldn't go back.

Our oldest son Arin, almost 21, said, "I do think nursing homes just want them to hurry up and die." And Jeff's colleague Boris said "They write him off". But I couldn't take him back and I knew that I shouldn't. And anyway, soon he'd have his room in Inglis House. Inglis House is not an old age home; it's a wheelchair community, for disabled people, often young disabled people. It's better set up for complete paralysis. Anyway, maybe Jeff was exaggerating. He'd exaggerated when he lived at home, all those criticisms of me. And he'd sometimes failed to communicate his needs. I hoped that's what it was.

It took the experts forever to figure out what our insurance situation was. There were several incidents, meaning upsets. Just before Thanksgiving, four months after nursing home placement, I got a phone call from one of the social workers. "Your insurance coverage isn't renewable. It's up around April." Thinking about it now, that made no sense, given the circumstances of Jeff's employment at the university. But I didn't know that; why would I know it if the social worker didn't? "Don't worry," she told me. "It doesn't matter whether it comes from Blue Cross or from a nursing-home grant?" She

meant Medicaid. But I already knew that Medicaid, fair as I've heard it is, is trouble for an already in-trouble family. It meant we'd lose some of our savings, maybe pension. It meant that, if Pennsylvania decided to pass a lien law before Jeff or I died, the kids wouldn't inherit the house. It meant I might not be able to teach a second course at Temple because I'd be making too much money to qualify. It might have meant other things that I didn't know about yet.

"I *can't* take him home," I said to the social worker. "I just can't."

"Don't worry; you won't have to," she answered. But for the past six years they had let me *have* him home. They had thought, or appeared to think, nothing of the awakenings twenty times a night, the thrice-daily lifting on and off the toilet (and wipings in between) with toddler Devin in the house. "Uh-huh", they had murmured. I had called this "the conspiracy of silence." That conspiracy had continued until I'd treated it as passive aggressive and taken my own action, in response to their *inaction*. I had said no.

But indeed, for a long time they had let me, in effect forced me to, have him home. So why should I feel assured that they wouldn't force me to take him back home now? Even though so much of the dire straits was over, I was still scared. Scared of losing my house, my kids, water, heat -- even my new lamps, the ones I'd bought at several flea markets because Jeff hadn't liked floor and table lamps and now he wasn't around. I was scared of losing my hard-won things.

Care giving had felt like rape; now visiting was beginning to. It was something I was forced to do. I had to take that six-dollar hour-long round trip twice a week. And Jeff was so miserable. Always asking for things -- more food, head-scratching, stretching, suc-

tioning, and did I call Boris and did I order that book? He'd been miserable at home. So if I were to take him home, it wouldn't help. I had to keep reminding myself of that.

Omigod, I'd think, what if we don't get the nursing-home grant? Well, thirty years ago I hadn't gotten a Yale fellowship. And I never got a Guggenheim or any lesser writer's grant. True, I'd gotten full-tuition-plus-fees at N.Y.U. and research fellowships to both N.Y.U.'s and Wesleyan's graduate math programs, but could I get a nursing home grant? And even if I did get it, how could even Medicaid afford \$10,000 a month? The cost seemed phenomenal for *anybody*, no matter how rich, no matter how much in charge. Nobody, it seemed to me, was above *this*.

Devin wasn't yet eight. He and I were very bonded and, when he wasn't sleeping with either of his brothers or over friends' houses, he was sleeping in "the family bed" with me. There was indeed still some degree of symbionic-ness, and that meant I wasn't very lonely. I had love in the house, most of the time. I didn't yet need to start dating.

I'll still never forget the night, in November 1993, Devin had an earache. We spent hours getting to, being at, and getting back from, the emergency room at Children's Hospital. It was a record winter, icy sidewalks and roads. We had trouble getting taxis both ways and the buses weren't running. At first, before they gave Dev a heating pad and Tylenol, it was horrible because he was in pain. But immediately after that he began getting frisky and the night turned into an adventure. He was filled with the wonder of it all and he said beautiful things like "Thank you for taking me to the doctor's".

"Yeah," I answered. "It's like a slumber party." We were both filled with the wonder of

it all. Another mother was there, who's little boy was also named Devin, a younger Devin, only nineteen months. Littler Devin had fallen asleep on the examining table; he looked amazing, black with pigtails. "My father says 'cut his hair, he's a boy' but I say 'I don't have a girl and I wanna plait his hair.'" This Devin's mother was also filled with the wonder of it all, in particular of her sleeping Devin. My Devin and I talked with her awhile; we wished we could have talked longer, wished we hadn't been taken so soon. In the cab ride home Devin said more beautiful things about that night. When we got home we both crawled into our "family bed" and cuddled up. I knew even then that this would be one of the motherhood things I'd remember most. I was also very aware that I wouldn't have to wake up to hand Jeff a jar or bedpan or "stretch" his legs.

Jeff had a busy schedule at the nursing home. "Busy work" can be very meaningful and important for the residents. So Inglis House kept Jeff busy, and me too. We made the rounds -- P.T., O.T., ham radio club, shul, "Friends on Wheels" support group twice a week, and discussions with doctors about a new wheelchair or what to put into the feeding tube. Jeff liked to have input into that last, and after a while it led to trouble. The busybody "friend" mentioned above got Jeff all riled up with regard to some diet the two of them had concocted, something which the nutrition staff insisted wouldn't provide all the nutrients -- and they could point to Jeff's horrendous bedsore to prove it.

Dev joined us at the Friend on Wheels meetings. It was kind of fun being an "Inglis House wife", a little like being a "soccer mom". Jeff and I would hold hands at the meetings. Dev and I got to know some of the other residents. Mary was an atheist like me

and we'd joke about it. Tanya, unlike me, had long nails; we'd joke about that. Bob collected candy and was always giving some to Devin. After our visit, the group leader Gail, Dev, and I would go out to dinner.

The other residents seemed to like Dev and me. We were the only non-residents in the support group; Gail had asked them, privately, whether they wanted us in the group and they'd unanimously voted yes. We did fun stuff. Gail brought in things like the Victoria's Secret catalog, and once I brought in some "sex game" I'd gotten at a thrift store; it contained various cards with questions and we all had lots of laughs. Gail had me give readings of my well spouse poetry and the residents seemed to like it. "I always wondered how the people who take care of us feel," they said. They had a sense of humor and their own brand of intelligence. Thelma collected photos of children and I gave her some of Dev.

For a very long time Dev and I were in the spirit, but years later that spirit got a little tired. And Jeff seemed to *never* be in the spirit. He did have a kind of dry humor, to his very end, and that was appreciated, or at least reacted to, by the staff. Mainly, though, he just didn't feel well. Still, I saw spirit in most of the other residents, who also probably weren't feeling well. I wondered. I also still remember the expression on Jeff's face as, decades earlier at Yale, he had stepped up to receive his physics Ph.D. diploma. I recall the smiles, broad or shy, on all the other Ph.D. recipients, and I remember my parents saying, "They all look so cute," and then, "Look at Jeff." Jeff had no smile at all.

Was it the M.S.? Had it been the M.S. all along? Or had Jeff just been extra-nervous at his Ph.D. ceremony? And was he extra-nervous now, living in the nursing home?

The first time Dev and I showed up at Gail's support group, she introduced me as a "Ph.D. mathematician" and then said "Do you know how she and Jeff got together?"

"Well," I said, "we met on a bus and started discussing math."

Gail smiled. I grinned. All the residents laughed. But I saw no smile on Jeff's face.

Debbie Hayden had a column in the well spouse newsletter; the topic for winter of 1993 was "How do you feel as a well spouse *parent*?" The replies would all be anonymous. "Proud," I answered. "That's the first thing that comes to mind. Eight years ago, when I and my big belly walked the streets alongside the 'trike' [meaning the electric wheelchair], I felt proud. And now, when Dev and I walk into the nursing home to visit 'Dad', pride is still a big feeling. It's the pride of being a mother, period, but it's also colored by the situation. I *chose* to become a well spouse parent and I've never for a second been sorry. Kids bring joy and humor into an existence that is becoming grimmer and grimmer."

There was one other fringe benefit not mentioned in my reply: Devin provided another reason, an excuse, for Jeff to go live in the nursing home. After all, we needed to "think about the children" -- that's society mindset -- far more than we need to "think about the mothers". "The children" need to live in an environment where Dad is not the center of attention and where whole pieces of shit don't turn up in the wash. Dev made my nursing home decision a little easier to explain and justify. When Jeff still lived at home, there had been a different fringe benefit: Kids attract home health aides; it's much more fun to work in a situation with kids involved. But my last sentence for Deb-

bie's column was this: "The only negative feeling I have about being a well spouse parent is: I'm a single mother, and an abused wife."

During the first week of January 1993 I was trying to get up the nerve to open up that letter. It was from the welfare department, about our application for a nursing home grant. First I had been waiting to receive the letter. "Oh, please, not today," my heart would beg when the mail arrived. I'd rationalize, "If it's in there I won't open it now because (1) I'm about to go teach, (2) I'm about to spend time with Dev, (3) I'm so relaxed and I want to keep it that way, or (4) I'm so tense; I don't need to add to the tension." Now, as I held the envelope in my hand, I just looked at it and stood there frozen. I'll open it later, I thought, in front of Jeff, or the lawyer, or the social worker. I didn't want to be alone with it. I don't remember who I actually opened it in front of. But what I found out was that the welfare department had not been able to decide. They needed extra time, more than the usual six weeks. Our case was too complicated, too unusual.

Sometimes the most difficult thing about visiting someone in a nursing home is leaving. The person doesn't want you to. As soon as leaving time draws nigh, he discovers all sorts of things that need to be done. Pillow adjusting. One more suctioning. And plant-watering -- too many of them lined up along the small windowsill, 'way at the other end of the room, between which and Jeff's bed lay an obstacle course of books, disability paraphernalia, and boxes of special food that Jeff was storing. Then there's something else he forgot to tell or ask you. "Just one more thing."

During the winters I was stricter about keeping to leaving-time, because it was cold

and dark; waiting for the bus was less pleasant, maybe more dangerous. That didn't seem to be a concern for Jeff; in fact, some of the staff would tell me just that, and they'd look out for me. One evening in January of 1993 I was a little late in leaving (probably because of an extra suctioning...). I knew I'd missed the bus so I decided to call home and let everybody know I'd be later than usual. "Oh, we're all about to go out," the kids said. "You can get home any time you want." It was a speaker phone so Jeff heard both sides of the conversation. "Oh, so now you can stay all evening," he said to me.

"No," I explained, "it's getting the bus I'm worried about; I don't want to take it too late." Then, to compensate for leaving, I set him up to talk on the phone with our friend Fran so that, just after I left, he'd feel better being on the phone rather than alone.

That night I had one of my recurring rapist dreams. A rapist was after me, there was a crowd of people, and nobody helped me. I went to the person in charge and told her the situation. "Well, of *course*," she replied. "You're a *phone*." I woke up trembling. The dream logic, I guessed, was "You arranged it so the phone replaced you. And this is your punishment." But it wasn't guilt that the dream was about; it was powerlessness. It was about what the crowd would think, and do.

I continued to feel slightly pressured to start dating. When I'd gotten married it had felt weird because I knew that everybody now knew we were having sex. Now everybody knew we were *not* having sex. I was wide open, powerlessly so. I didn't at the time *want* sex. But my friends didn't understand that -- or maybe they didn't. Certainly, I knew, they were watching me, waiting for me, wanting for me what they perceived they'd want for themselves. It was the least of my problems.

In his grief journal over his wife, C. S. Lewis wrote “I am *not* frightened but I feel as though I’m frightened.” Sometimes my version of that was, I am *not* grieving but I feel as though I’m grieving. In some ways, of course, I *was* grieving. I was grieving my youth, my years of mothering young children, my marriage. There was definitely loss. But it was a more general, more gentle, more chronic kind of loss. Nothing like my baby Kerin back in ‘77. It wasn’t horrible grieving but it was still grieving.

In February 1993 I dreamt I was looking in the mirror. In real life I’d been having a lot of “good-hair days” and in general felt pleased with the way I looked. So now, in the dream, I was looking in the mirror, walking right to left, facing different angles, and then I saw another face in the mirror. It was the face of a handsome man, just the right age. He caught, literally “caught”, my eyes in the mirror. And he *kept* my eyes, kept looking at me, and I him. We looked at each others’ eyes, flirted like that, for awhile.

But then he said he wanted us to get out of the mirror. I didn’t want to. I tried to just walk out the door, pretending none of it had happened, but he spoke. He said “You’re just so attractive.” I gave in and met him outside the mirror. But now I avoided his eyes. The reflection of his eyes I had been ready for, but not his actual eyes. Still, I was becoming ready. “Here it comes,” I thought. “He could be someone I love.”

But the dream ended like that other one. He said that he knew my books; he’d read “The Sitting-Down Hug”. He added that he was a doctor specializing in disability. Also, when I finally looked at him, he had changed. He wasn’t handsome like the man in the mirror, but rather homely. No, I wasn’t ready and neither were any of my dream men.

Jeff and I had a social life in the nursing home. And there was gossip. Mary told us about Gary, how he was in love with Jackie, had propositioned her, asked her to go with him to the Privacy Suite. Mary seemed angry about that and so did Tanya. "All men are pigs," she blurted out, and we all laughed. "Except Jeff," she added.

This Gary was a friend of Jeff's. Jeff spent time in Gary's room watching pornos. Jackie would join them. "Did he ask you, too?" Mary asked Tanya.

"No, thank God," Tanya exclaimed, and we all laughed again.

Jeff was having more and more trouble talking. He had less wind. His words weren't slurred, just too soft. "What?" Joel would ask him on occasion. I didn't want to be Jeff's interpreter. But in the group I usually sat next to him so I was the one who heard him best. I wasn't thrilled with the role that put me in. Moreover, Gail asked me whether I'd like to volunteer to be a feeder at the Monday night dinners. I'd feed the residents. How, I wondered, could she ever fathom I'd be interested in that, after years of feeding Jeff at home? I realized anew that "Friends on Wheels" was not a support group for me.

Home life with the kids was very good. We all really loved one another. Dev's older brother, fourteen-year-old Bret, was growing up, but he also still sometimes asked me for "finga" (meaning he wanted to hold onto my finger) and "a little while" (meaning, time alone with me). He would smirk as he did so. Bret and Devin would play this game; they'd "kidnap" me, lead me by the hand up to Bret's room where we'd hang out, play games, read, or watch TV. "*You* take her other hand," Devin would say to Bret. "I'LL

make sure she doesn't go into the bathroom." In February we made Valentine cards, the one-page kind that kids bring for the Valentine Box in school. We drew pictures of a pencil and the caption was "If you won't be my Valentine, what's the *point*?" Or a floor-board with the words "Valentine, you really *floor* me. *Wood* you be mine?"

All very good. But I didn't always feel good. Sometimes I felt existential, unreal, distracted. And sometimes I'd ask myself, "What am I doing *most* of the time?" I wanted there to be something I was doing most of the time. Things probably just weren't settled enough. There were too many surprises. One week in March 1993 Jeff was hiring his own personal assistant for too many hours, too much money. "Bill's the only thing I've got," he'd say. I considered not letting him have any checks so I could be in control of paying Bill.

One day Jeff asked me, "What about that hospital bed?" He meant the one in the room opposite our bedroom at home. It was extremely heavy and voluminous, turquoise blue, and only half blown up; it looked ridiculous and was unusable as a bed, for the kids' friends to sleep over or for anything else. I didn't want it in the house, not above cellar-level. But "I want it for when I come home," Jeff would say. "It's *my* room."

My friend Freda said, "Marion, you don't need that hospital bed there to remind you of Jeff". I didn't need that bed, period. Eventually I got it taken down the cellar, then finally carted away. But that was years later. And it was on more than one occasion that Jeff would ask, "What about" such-and-such a book? For a long time I was afraid that, although it was soon apparent that he didn't really want to come home even for a visit, he'd somehow discover it if I got rid of anything that he obsessed on. I got more and

more bold but it was only after he died that I felt completely free to get rid of the things that I no longer wanted. It was only then that I felt that the place I lived in was mine.

Previously, when “Dad” still lived at home, the kids would derive a kind of therapeutic nervous fun out of “playing Dad”. “Mar,” they’d go. “Jar.” So now they’d “play nursing-home Dad”. For example, the voice-activated mechanism that “Dad” used. “T.V.” “Phone” “VCR.” The kids would mimic that, adding “Jar”, and we’d all go into hysterics.

“Jar isn’t one of the choices,” we’d imitate the machine.

“I don’t care. I want a jar,” we’d imitate Dad. We’d laugh and laugh and I probably never stopped thinking, “It’s okay to do this. It is okay.”

I knew that the kids would grow up more and more. I knew I wouldn’t always be having people I loved living with me. If I didn’t marry again, or didn’t get a housemate, I’d live alone. Maybe I’d become a recluse. A whole different sort of being. Maybe I’d start stuttering again. Maybe children and grandchildren and writing and therapy and singing and thrifting wouldn’t help. Suppose even math wouldn’t help? Suppose I got so alone and scared that I couldn’t function, in particular teach? Suppose I forgot to eat and drink? Suppose I just forgot I was in the world?

A friend of a friend asked naively, “Don’t they have provisions for the whole family to stay at Inglis House?” I didn’t know whether to laugh or cry. I finally simply explained. “I don’t think we’d want to live at Inglis House.” I went into some details and when I was alone I had fun fantasizing. “Hey kids, guess what? We’re all gonna go live at Inglis House with Dad.” How their faces would fall.

True, maybe Inglis House would do it right, give us a nice apartment with more than one room and not put me in charge of Jeff. Maybe, in fact, they'd do it really right and I wouldn't have to cook; they'd figure I'd put in my due and now this was due me -- society's chance to express appreciation. Maybe they'd even publish a book of my poems. Maybe I could even be, literally, their "resident poet" -- a paid position. But even if they did all that, it wouldn't tempt me, or the kids. Not even a little bit.

Another dream, April 1993: Freda and I were in her car, on one of our thrifting marathons. We'd been talking -- mostly about Jeff-- and we continued talking even after she parked the car. Eventually I asked, "*Now* can we start shopping?"

Once in the store, though, there was a workshop going on, a workshop I was supposed to lead, on chronic illness. Everybody hailed me as the expert and I felt happy. Eventually, though, I again asked, "*Now* can we start shopping?"

Gail seemed to think that, just because I had waited so long to insist that Jeff go live in a nursing home, that meant I found it hard to stick up for what I wanted. It was a stereotype that many people seemed to hold to, and it hurt me. They didn't seem to understand the phenomenal-ness of the obstacles in the way of nursing-home placement and that, considering them, I was indeed very good at things like knowing, doing, and insisting on what I wanted. I had fought hard against the "conspiracy of silence". I had very clearly told social workers, doctors, anyone I perceived as being in charge, that I didn't want to "do this" any more. And I had finally stopped telling and simply refused.

Other well spouses do understand. Moreover, some have said to me, "It's amazing

how, in the midst of it all, you continued to do things.” Yes, even before insisting on nursing-home, I insisted on writing, publishing, lecturing, doing math, mothering, and thrifting. I never forgot about what I called “the me in me”. Like all human beings in many situations, I had to evolve to nursing home, and I did evolve.

What I was evolving against was a type of abuse. I didn’t consider the abuser to be Jeff. Rather, it was society and the health care system. I was taken advantage of, I was oppressed. I saved the system a lot of money by holding out for so long while they had kept to their conspiracy of silence. I was, in the words of someone in the audience at one of my readings, “a cheap date”. And thinking about that sometimes still hurts.

Back to Gail and so many others, didn’t they notice how I acted with Jeff? How I was definitely considerate of him but didn’t let him dominate me, didn’t even always sit next to him in the group? There were pressures on me to, but I didn’t. Also, I didn’t visit him every day, but welcomed what the social worker had told me when he was first admitted; “twice a week is just fine. If you visit him every day, he won’t get the chance to make Inglis House his home.”

True, I had done nights, lifting, and toilet for six years -- and holocaust victims were in concentration camps for years. There was no choice, no opportunity to stick up for what they wanted. In other words, I felt that some people were blaming the victim. And it hurts to be blamed. Yes, it does feel like blame. Or at any rate, not praise.

That month, April 1993, I dreamt I was throwing baggage off a train, four or five suitcases. But when I’d finished throwing them off and had jumped off the train myself, I saw that the baggage was still moving, in the direction of the train -- more slowly, true,

but still moving. I, too, was being moved in that same way. “Maybe I didn’t throw and jump far enough,” I thought. “Off the train isn’t enough; it has to be off the tracks, too.

Yes, maybe it wasn’t enough to merely “throw” Jeff out of the house, or “throw” poetry submissions into the mailbox. Maybe I had to throw them *further*, though I wasn’t sure how or how far. Why do dreams ask more questions than they answer?

Jeff often had to go to the hospital because his J-tube would get dislodged. I’d usually go with him or meet him there. I didn’t always want to but Jeff believed he’d need somebody with him to explain things to the ambulance and the hospital people. My publisher had called Jeff a “Jewish prince” and Gail had said she’d never met anybody as manipulative as Jeff. Once I told Jeff I didn’t want to go, the kids were expecting me home. But Jeff was scared. And I was moved when he asked the ambulance people whether they could drive me home and, when they couldn’t, he suggested I take a taxi (very uncharacteristic of him). He thanked me again for going with him and, when I got home, called to make sure I’d arrived home safely. And what stuck in my mind was the feeling of leaving the hospital, how we had gone our separate ways, he to his “home”, me to mine.

Some visits were good. We still shared our science careers. He still said “Don’t worry, Mar, you’re okay” and “You’re the best teacher; that’s obvious.” But did I love him? I felt that I *knew* him, but was to know him to love him? One thing I was sure of: When he was gone I would miss him. Four years later I was sure of the very opposite.

One night I dreamt that Jeff was dying; I kept saying, “O, I love you. I love you. Don’t go. Don’t go yet.” But I didn’t mean it. I was only acting.

That same month I gave a presentation about the Well Spouse Foundation to a group of geriatric nurses at Presbyterian Hospital. It was part of some meeting they were having. As I was talking I felt great but immediately afterwards... well, there I just was, in the midst of *their* business meeting. They were being paid to listen to me but I was not being paid to speak to them. They had full time jobs and I didn't.

"It must be nice," I later said to my daughter Marielle, "to have a regular job. You just go to work and whatever they need from you they ask for. You don't have to apply or submit or hope they remember to think of you."

"Yes," she answered. "I don't have to keep seeking things out. It does feel great." In the thirteen years since then, I've had one full time job, several parttimes, some new books including one forthcoming as of this writing, and I still don't know that feeling of not having to seek things out all the time. It must be great.

Was there something wrong with me? Meaning, the way I felt about life in the nursing home. Questions kept occurring to me -- existential, Kafkaesque, and, perhaps, *mean*. Like, why should I spend all this time and energy trying to hear what someone with severe C.P. is trying to say when that person doesn't have anything more interesting to say than someone without C.P.? Yes, that is mean. And the answer is that things to say don't have to be interesting. Also, the person is a human being. Also, I'm a human being. And, in general, a compassionate one.

But I'm not *only* compassionate. I have other feelings, too. All my life I've been aware that, just as there are colors besides the main six, there are feelings besides joy, sor-

row, love, and compassion. There was something surreal and nightmarish when I'd ask one of the Inglis House residents where 2 North Solarium was and he'd say, "I'll take you there." Well, I didn't want him to take me there. That meant having to wait with him for the elevator -- a long time because his wheelchair probably wouldn't fit in the next one that would arrive -- and having to make conversation when my mind was on what awaited me in 2 North Solarium. It all would take so long; everything had to be slowly, like ranging Jeff, and I wasn't the slowly type. Yes, it was poignant, the pleasure he got out of helping, but it wasn't *only* poignant. Besides, maybe he was trying to impress his friends by being seen with this "beautiful woman"; that kind of thing actually did happen quite a bit at Inglis House during those years, and I was never a willing participant.

That 2 North Solarium incident reminded me, at the time, of something very painful from my adolescence. I was fourteen, not yet dating and desperately wanting to be. My girlfriend Diane took me to one of her parents' relative parties; she had a distant cousin, a little boy about nine who had C.P., and he developed a crush on me. He kept following me around. I had to be nice to him; he was a child, with a disability. I played along, probably smiled, but inside I was miserable. I felt full of hate for my dateless life. At one point the boy put his arm around my waist, which didn't sit well with me at all, since I was tall. "I don't want this," I thought. "It's not *this* boy I want. I want a tall boy, a boy my age, a boy I love, a boy I've chosen. I did not choose him. I can't stand this. This is *rape*." I hated having to pretend I wasn't feeling that way. I would much rather have stood up for what I wanted but, as in the 2 North Solarium incident, there was no way to do that without hurting feelings and being looked upon as selfish.

I wondered whether any of the residents ever had deeper thoughts. Did their diseases preclude that? Or only the expression of that? “Every one of the residents has something mental going on,” some of the staff members said to me, under the table. The residents, including Jeff, would all pass “psych-evals” -- much to my frustration and detriment, as you’ll see later -- but yes, I agreed, they all seemed to have “something mental going on”. Were they so in the throes of their diseases and paralyses that there was no room to think about anything else? Would I ever get to really know any of them? Or did we, ultimately, speak different languages? Were they all, as I had said in a poem years before, “separate species”? Was I on a foreign planet?

But Devin and his stories were just great. He danced around a lot, not hyper, just happy. “Mom, guess what. Fireflame turns out to be bad.”

It kind of threw me. “Really?! Fireflame?!”

“Yup.” The Fireflame stories were usually violent. On every page somebody got killed (or “almost killed”, Devin would have me write). But Devin wasn’t violent; he was sweet about his stories. Probably they were about what he knew, or what he was afraid of. “Next day a giant head sucked in Futuristic and Robot Surfer.” “Next day a man with spikes instead of hands almost killed Snow King and Fire Hand.” Even Sally turned out to be bad. “Sally?” I exclaimed. Please, not Sally. Not the same Sally who’d given birth to twins. “Yep, Sally,” Devin answered with a slight smirk. But the good news, said Devin, was that Sawing Brother got un-hypnotized. Or Fireflame turned out to be alive. Or it was just Sally’s dream. And sometimes he’d give us a break. “Hi, I’m Futuristic. Can you do this maze?”

My favorite characters from Devin's stories were King of the Heads, Killer Machine, and "a man with air as his legs". When I was a kid I didn't write like that. I wrote stories about Mary and Sally, two perfectly human little girls. When I was nine I wrote, "Every room in Bobby and Billy's house has a light in it. They only turn it on when it's dark. They don't turn it on when it's light. They only turn it on when it's dark." When I was eleven I wrote an "inner life" autobiography and, inspired by my mother who gave me a copy of Anne Frank's diary, began the diary which I still keep. I must have known I was a writer. And I must have known, already, what my mother had told me. "Sometimes it's not happiness, not sadness, not confusion. Sometimes it's just a feeling." I must have given myself permission to feel things that were "just feelings" and perhaps that's why, now, I had permission to feel not only compassionate about the residents of Inglis House but also things that some people would call selfish.

August 30, 1993 was Jeff's and my thirtieth anniversary. Well spouses sometimes talk among themselves about their anniversaries, and we raise our eyebrows knowingly and sometimes laugh. It's what I call funny-familiar. Our marriages are often virtually over and anniversary celebrations feel hypocritical. For us, it was the first anniversary that we weren't living together. Marielle, our oldest, still gave us a little party in Jeff's room. The six of us crowded around that high bed and ate cake. Marielle gave us a wooden salad bowl set. As I opened the package she looked at me knowingly and said, "I know..." For the set would, of course, be used only by me.

Three-fourths of the way into Devin's "Futuristic Long Story #3", I could see that he was running out of ideas. "Ya know," I told him, "you don't have to wait 'til the end of the notebook to end the story."

"But then I'll have all these other pages," he answered.

"Oh, I see, you're worried about wasting the pages."

"Yeah."

"Well, you could just use them for another story, or for pictures."

But Devin decided to use them to end the story. On the very-next page he wrote, "the end", on the one after that "It's still the end," and then "it's the end already." He kept thinking of variations on that, for a total of thirteen pages. It was a very long and chronic end, like his father's. Maybe Dev believed all ends had to be like that.

"It seems like the family's falling apart," said Bret. Once again, I geared up to give an honest but hopeful answer. "Well, there's a lot of change taking place. Dad, and Devin's growing up, and you, mostly you... I remember when I was thirteen. All the usual things that the family did, they just weren't the same. Meals, trips we took, it all just felt different. Things were changing and I was changing. Sometimes I wish, instead of nature 'n' all being the way it is, I wish everyone could just be the same age forever and ever, and families could be the way they are." I shook my head to get out of too much pensiveness and to begin anew. "But we can still be a family. We can change with the changes, and we can still get together and have fun 'n' all. Sometimes it takes time, though..."

I had come up to say good night. I was also looking in the dark for Devin's pajamas. On one chair I thought it was pajamas and it turned out to be a cat. On the next chair I thought it was a cat and it turned out to be pajamas. I had been starting to pet the pajamas. Bret and I laughed for a long time. Yes, indeed, we could still "have fun 'n' all".

Every once in a while some Inglis House resident who was not Jeff would ask me for something. Gary wanted me to take off his shirt, somebody would ask whether I could take a particular piece of paper out of her bookbag. I didn't like it but only once did I truly hate it. Somebody asked me to light his cigarette. The lighter didn't work. I'm sure it wasn't just me. True, I have never smoked and true, I had never learned to snap my fingers, but I certainly knew how to flip. And he kept asking me, in the same voice that Jeff used when he asked for something again and again, that same monotone, same expression-less face. Why, I wondered, do the residents, including Jeff, have such expression-less faces? They're not paralyzed above the neck. Their faces were all they had left; why didn't they use them? Maybe people don't like to use all they have left.

CHAPTER II: THE ULTIMATE CLOSURE, SO FAR

Six months after Jeff went to live in the nursing home I decided to write a memoir. I'd already published well spouse poetry books. But I wanted to reach a wider readership, to try to convince society that at-home caregiving isn't as feasible as it seems to think, that those who do it need 'way more support, and more importantly help, than they get. "Dirty Details" would be prose and, I hoped, published by a mainstream press.

Every morning I got up at 6:30 AM, before Dev woke up and before I needed to leave for teaching. I worked for a couple of hours at the kitchen table on my Daisy Wheel typewriter. My sources of information were my diary and recent memories. I wove them together at rocket speed, a chapter a day. After eight chapters, I spent an extra month going over it all. In six weeks the first draft was completed.

I sent out my first query letter, plus sample chapters. "The best way to describe my vision for it," I wrote, "seems to be to compare it to presentations I've given to groups of nurses and social workers. I tell them what well spouses go through and what we talk about at our support group meetings. I always long to tell more and this book would give me that opportunity." The first press was interested, and asked to see the entire manuscript. I sent it out right away and then began to wait.

In June of 1993 I read my well spouse poems at a disability conference, coming from the perspective of the family. Many of the attendees had disabilities of various kinds. Disability culture and politics abounded. The prevailing philosophy was positivity; if

given the choice, many said, they would not give up their disabilities. I knew that, if Jeff were given the choice, he'd give up his "disability" in a heartbeat.

After the reading, a bunch of us went out for lunch and shopping. As we were getting out of the car to step into the restaurant, somebody without a disability said to me, "I know exactly what you mean. I used to be in a relationship with someone who had a disability and I was a *basket case*. It was horrible. I finally got out of that relationship and... of course I'd never say this to anyone here at this conference -- but... *never again* ... Just being honest," she concluded. "That is, being honest with *you*. I realize I'm not being honest with the rest of the disability movement."

"Hm," I answered. I was rooming with a woman who had mild C.P. She and I got along well and I'd asked her feedback on some poems I was considering reading. I'd needed to make sure I didn't say anything politically incorrect. One of the poems under scrutiny was "3:00 - 5:30 A.M", in "Epsilon Country". It begins, "Turn him. Toss him. Stretch him. Shrink him..." and continues "When he finally drops off, he talks. 'Mar? 'Bret?' 'Is the jar still on?' 'Are the covers still off?' / And I lie here and think what it must be like to be locked inside that epsilon neighborhood... And then I think how, when you die, you stop breathing... it must hurt not to breathe, even if you're dead... Maybe," it ends, "maybe in my will I'll leave instructions for everyone... to connect me up to a breathing machine. And maybe I'll also tell them to turn me every two hours/ stretch my legs, straighten my arms, open my hand, close my eyes, scratch my nose, two jars and three bedpans / so it won't hurt quite / as much."

“Oh.” My roommate sported a worried frown. “I think you’d better not read that one. I think that one would be construed as being negative.”

I considered. “But the poem isn’t meant to be negative about *disability*; it’s meant to be negative about the human condition. We’re all vulnerable, powerless, and fearful in some ways, able-bodied people too. Negativity exists for all of us..”

“I know,” she answered. “You’re right. But I don’t think people here would interpret it that way. I just think you’d better not read that one. I’ve had run-ins with people about that kind of thing.” Indeed, that had been one of my caveats about this business of feeling positive about one’s disability. I’d been concerned that people with disabilities would be so cautious about expressing negativity towards their disabilities that they’d wind up unable to express negativity towards anything at all. People with physical and/or mental disabilities don’t need to acquire emotional disabilities as well.

Back to Jeff: One day that summer I went to our bank to withdraw from our joint checking account, where Jeff’s monthly checks got “direct-deposit-ed”. I saw from the balance statement that the check had not been deposited. I spoke to the bank manager, who phoned the appropriate department. No, the check had not “come in yet”. I went home and called payroll at Jeff’s work; they didn’t know. “Call back Monday -- Ask for Roz”. My main concern was that Jeff would be worried that somehow the university had decided not to pay him anymore. But at the same time I also thought, “Maybe somehow Jeff is behind this.”

It turned out that he was. On Monday Roz at Payroll told me, “He changed the account where the checks get deposited. I’m sorry, I can’t give you any other information.” She seemed slightly embarrassed.

“Oh,” I said. “I understand.” Yes I understood, in more ways than she knew. This time I was able to straighten it out with Jeff, and with those whom he claimed “made a mistake”. It took weeks. So I began trying to convince Jeff to give me power of attorney. I had heard too many (true) stories of people with dementia impoverishing their loved ones. Only the spouse recognizes the dementia and the tests they give aren’t sharp enough to reveal it. The consequences are dire.

“I trust you more than anybody,” Jeff once told me, “but I still don’t trust you.” Our lawyer had recommended that he give me power of attorney, but he didn’t trust the lawyer either. And he couldn’t bring himself to sign anything. Over the next two years I kept trying and, to skip ahead, I finally succeeded. More accurately, it all finally sank into Jeff’s brain. In fact, it often took a very long time for certain things to sink into Jeff’s brain. I had to repeatedly go over the logic, along with what I was feeling. That also had to be the route taken to get him to put the house in my name. As you’ll see, my former therapist, who specializes in chronic and neurological illness, eventually confirmed this perception; that’s the nature of some forms of dementia, she said.

Dementia goes in and out. And it selects its arenas. Jeff was not cognitively impaired every minute; he was sometimes quite the opposite, even in emotional ways. In July of that year, for example, he volunteered to me, “I understand how hard it is to visit twice a

week. I remember visiting you in the hospital after you had Dev. I was exhausted and it was only for one week.” Yes, dementia can go away, and it can come back.

I wanted to give the kids a vacation that would at least begin to make up for everything -- having a Dad in a nursing home, all those home health aides living in our house, Bret having done all those nights with Dad, and Devin having, even as a baby, been aware that Mom had so much on her hands already, so trying to be extra-good and not bother me when he was hungry or scared. So we began a yearly routine of vacationing for a week at Rehoboth Beach in Delaware.

Walking along the boardwalk, I put my arm briefly around Bret. “I’m lucky,” I said. “You’re fifteen and you still treat me like a mom.” Bret nodded. “When you’re growing up,” I continued, “things sometimes start to feel different. Even if they’re not different, they might feel different. Like with Elle, and with Dad, I’m sure. Maybe even with me.”

“No,” -- Bret looked down. -- “not with you -- ‘cause you *realize* that.” Of course that felt great! But I still wondered: Did I give the kids a good enough vacation this year? Sometimes I felt as though I were performing for them. When you’re a mother, it’s so easy to slip up; slip-ups chase us. And soon we’d all be visiting Dad again.

That fall semester I got embroiled in a new math problem. I was already embroiled in at least one *old* math problem, the one from high school, what I called “alternative arithmetics”. The new problem was different, very visual; it wasn’t geometry or topology but it wound up being “modeled” by points and lines. I called it “characterizing comparability”. I had no idea whether or not it had been worked on or solved already, and I didn’t

care. I wanted only to experience it. It was wonderful, and terrible, being in those throes. I thought about the problem most of the time, even as I taught the much simpler calculus, interacted with students, visited Jeff, talking with him a little about the problem, even as I was enthralled with my kids and the things they said. I wrote poems about what it felt like to be so embroiled. "Points were blinking. / Lines were beckoning. / How was I to know? / What was I to do?..." I poured my guts into that math problem and those poems. I also continued writing in my diary, though not quite as much, and what I wrote *about* was my thought processes working on that problem. During those months, in fact, I developed the habit of writing on only one side of the page. The other side was reserved for any ideas I might get regarding the problem.

The press that had been considering "Dirty Details" wound up rejecting it. "It's too angry," they wrote. "You're definitely justified in being that angry, but our readers would have trouble with it." So I sent off another query to Temple University Press. A week later the phone rang; it was one of their editors. Yes, they were interested but needed to see the entire manuscript, and they also wanted to know, "How is this book different from all your poetry books about being a well spouse?"

I thought fast. "Well, first of all, it's not poetry! So I'm hoping it will reach a wider audience. Secondly, I say different things in it. In particular, I say on no uncertain terms that society expects the impossible from at-home caregivers, and the health care system and its professionals don't do enough to help. In the last chapter I talk about how my family and I had to figure out for ourselves that it was nursing-home time." That kept the

interest I had apparently sparked. The next step was to send out the entire manuscript, and to again begin waiting.

In August of 1993 Jeff had lived in the nursing home for a year. Things were more settled now, and feeling safer. And I finally got rid of those wires – meaning the ones next to Jeff’s side of the bed. I’d never gotten used to them, had had many a tantrum over them. Jeff had supplied a *raison d’être* for every one and who, in the midst of toilet, had time to argue? Well, now I didn’t need to argue. The wires were going to go. I glanced at that nook of many wires, and, good-natured-ly, attacked. I dove into the middle of it, picked one, traced it, both directions, to its ends. Then I picked another and did the same thing. I had to do a lot of un-knotting. As I worked, I laughed happily. It felt a little like a treasure hunt. I was acquiring space -- Ah, lovely space! Some wires led behind the heavy bookcase or were plugged into strange monstrous devices and I worried a little before unplugging. Still others turned out to be completely disconnected, both ends, and when that happened I laughed extra-heartily. And soon I was free!

The next time I visited Jeff he mentioned that, in five years, he’d be better and would be coming home. “Uh-oh,” I thought, in particular about the wires, but then I said, “Well, you’ll find the house a lot neater than you remember.”

“Good,” he answered, being in that kind of mood.

The wires were gone, but there were still those “moons” -- meaning certain ceiling lamps that Bret, Devin, and I hated, and about which Jeff kept saying, “Don’t get rid of the ones in my room.” And there were still (and, as of this writing, there continue to be) nightmares like the one of burying something under the ground, something that must not

be discovered, and realizing that the earth was transparent. There was still the unacceptable stuff that Jeff was going through, all week long -- and Boris, his very best friend and physics colleague, only friend of his who was also a friend of the family, died of a sudden heart attack. Yes, Jeff's "details" were *not* "less dirty"; in fact, they'd get, over the years, more and more dirty, dirtier than mine had ever been.

Subtle dementia often doesn't affect scientific reasoning. Jeff could still discuss physics and math, and he still worked on papers -- though once a rejection letter came into my mailbox; "these ideas were already done by you 30 years ago." He could still often remember names, numbers, and what happened both last week and in his childhood, but he sometimes couldn't remember whether or not some particular incident had happened and how many times. He could still watch TV, getting the correct channels via the blow tube. And he could still ask me to please adjust that blow tube, make sure it didn't bump into the three other tubes that hovered near his mouth. He could chew and swallow but not drink. If he did, the fluid would go into his lungs so he had a J-tube for liquids. His fingers could still grip mine. I knew it was just a spasm but it still felt nice.

Whenever I was arriving home I'd suddenly panic. "Please. Not a rejection from Temple. Please, not today." It reminded me of waiting, 35 years before, for Jeff to ask me out for the following Saturday night. Every time the phone rang I'd clench my fists. "Please make it be Jeff. Pleeeeze." I'd repeat that maybe a hundred times. Now, of course, when it *was* Jeff rather than Temple U. Press, I was in agony.

One morning I got in the mail something which, though I was petrified to open, I did. The letter began, "I have the same positive reaction to your entire manuscript that I had

to the samples... The manuscript is now in the hands of outside readers.” I felt happy but immediately cautious. Suppose one of the “outside readers” was a well spouse who weren’t as honest as me about her feelings? Or simply somebody like that other press who’d thought I was too angry for its readers? On the other hand, maybe it would be Maggie Strong, founder of the Well Spouse Association, author of “Mainstay”, and friend of mine. I hadn’t gotten any full time jobs, but maybe this was something I would get.

My publisher Roberta, though, got something for me. She got a grant to do an exhibit of my well spouse poetry, along with Anna Moon’s care-giving photos, the ones she’d taken at our home during the year before Jeff went to live in the nursing home. The exhibit was in Roberta’s “home/studio”, a huge dark loft filled with thanatology books, papers, Day of the Dead sculptures, and paraphernalia such as a real coffin she’d found on the streets and made into a bookcase. Enough people showed up to fill that large space. Along with the exhibit went a small chapbook, “Extreme Points”, consisting of some of my well spouse poems and Anna’s photos.

As a joke, Roberta had made a blow-up of a New York Times front page; next to a grinning photo of me appeared the headline “Extreme Points Wins Pulitzer Prize; Author Marion Cohen thrilled”. My first reaction was, crazily, “Oh! I won the Pulitzer Prize!” Then I realized it was a joke. But it didn’t seem funny to me. Instead I felt rather sad and insulted. “Well, why NOT?!” was my second reaction. Also, nobody from the Well Spouse Foundation had come to the exhibit. And, of course, Jeff couldn’t be there.

For Thanksgiving 1994 he wanted us to bring him food from Tandoor India. But food to go is never as good as food on the premises and this was no exception. They pack it

in little bags without handles, and not much room at the top to *make* handles. And the bags leak. The relishes and chutneys are in tiny containers and never enough of them. They forget to pack forks, napkins, and worst of all, the samosa. Sometimes they pack *too* many forks and napkins; they take up too much space in the bag. Also, the bags are exactly the same size as the plastic containers so you can't reach under and lift them out, you have to grab the lid-rims with both hands or just tear open the bag. And then it usually rips too much and other things spill out. Moreover, what the most demanding kid wants is always on the bottom. I knew Jeff wanted it to be like old times in Tandoor India, but it just couldn't be. Not even close.

The well spouse life feels very downtrodden. I wanted something really big to happen. I had sixteen published books and chapbooks but none from a mainstream press. I wanted big potatoes. It seemed to me that small potatoes were chasing me. I envisioned them as sallow whitish yellow, like the stuff in Jeff's suction tube.

I had my family, I had my friends, I had my Roberta, and had had Art Ide before his Liberal Press folded. It seemed to me that all that was tender was powerless.

But I solved that math problem. I characterized comparability. "Eureka!" I wrote in a poem. "Pretty Eureka! Pretty Eureka with sugar on top!" I owned it. I still own it. I think it's the best and hardest math I've ever done, including my thesis and that alternative arithmetics problem. I usually thought, and still think, of myself as a "theory-creator". Mathematicians are sometimes classified into two categories: theory-creators and problem solvers. My Ph.D. thesis had been a theory, and so is alternative arithmetics. But this was *a problem*, and I solved it. I had not quite known that I could.

Devra, a mathematician friend, looked it over, made some minor suggestions, then said, "Congratulations! It's a great piece of mathematics!" She gave me the name of somebody who worked in graph theory who could tell me whether or not it had ever been done. "Graph theory?" I said. "I didn't know it was graph theory!" But it was. And that somebody wrote back that it had been done. I didn't and don't really care, not very much. Because I still own it. Also, I'm not sure whether it was done for infinite graphs. My theorem covers them, too. I should look it up but I haven't. I just haven't. What I own is the theorem and a forthcoming book, "Crossing the Equal Sign", consisting of the poems written while I was working on that problem. That's what I have to get and give.

Back to December 1994, just shy of a year and a half of Jeff living in the nursing home: one day I started to tell Bret that I'd felt sad when no one came to the choral concert to hear me -- no significant other, that is. "Nobody comes *with* me," I said. But Bret interrupted me with "Oh, Mom, don't start in again..."

I hadn't known I had ever before "started in". I understood how kids can be and how hard it is for them to see their parents hurt, also they might be afraid I'd have another tantrum. (It had been a couple of years since my last one.) But maybe, if I were published by TUP, they wouldn't view me as a burden. At least I would find out.

There were other things I wanted to find out. What an academic press does for you. Whether it gets you reviews in newspapers and spots on big TV programs. Whether it gives advances. I knew only small presses. And what I knew was: They're very small.

On December 15 I heard from one of TUP's outside readers, along with a cover

letter from the editor. “I cannot imagine a stronger review.” I re-read it again and again. From “My recommendation? Publish it!” to “This book changes how one thinks about caregiving” to “it could be the best crash-course for professionals” to “I’m worried that we’re contributing to the ‘conspiracy of silence’ that Marion describes.”

I read it again and again. Finally, finally, big potatoes! Finally I was being listened to by people in charge. It represented validation ‘way beyond Jeff being placed in the nursing home and the staff all exclaiming, “How did you ever do it all those years?” Still, that was only the first reader. And after my initial euphoria it was back to waiting.

When I shared my news with others, different people said different things. Nancy: “I bet they publish it.” Joseph: “Oh, the outside readers aren’t gonna go out on a limb and tell them not to publish it; they almost never do that.” Jeff was already planning on selling a million copies. But Maryam said “Oh, you still heard just from the *first* reader?”

I was seasoned enough to take it all with a grain of salt. But I was also extremely sensitive. Marielle said, “So many things with our family build up and then don’t work out.”

She was referring mostly to Jeff’s things. His solar collector invention which never got marketed; he was always connecting with the wrong business people. The various academic positions that he said were offered him but which he somehow never actually took. I wanted so badly to be able to tell Marielle that my TUP book had worked out -- the book itself, not only that wonderful report from the first reader as my only souvenir.

I worked hard to keep my perspective. I reminded myself that those six years of nights, lifting, and toilet didn’t entitle me to get the book accepted. Things just happen, the TUP editor wasn’t specifically looking for an outside reader who would say no, he

wouldn't keep looking 'til he found one. It would do no good to bargain with God or fate, even as I understood that I was *not* bargaining; I was begging. I also reminded myself that if the book got published, admiration wasn't love; I would still eventually want love.

"That's a really good press," said Nancy and Kitty independently. "A very prestigious press," said Relli. All that made me even more unbearably ambitious. In those weeks I didn't feel like doing housework, let alone make doctor appointments for Jeff. I didn't feel like "doing my part" until the world did its part. The waiting and the absence was driving me crazy. I wasn't a teenager waiting for Jeff's phone call but I was, in spirit, a teenager, period. I was young -- for all practical purposes during that period, too young. And powerless. The world was doing range of motion on me, too slowly. Like a woman in labor I pleaded "not much longer, please."

My first therapist had said, "I can see why you're a writer and a mathematician." She didn't have to say more. My life has always been such that I feel the need to prove things. Prove to my parents that I wasn't wrong. Prove that the baby dying wasn't my fault. Prove that I had the right to not do nights, lifting, and toilet. In January 1995 I dreamt that I decided to take a break from it all, go down the cellar, settle in with old letters, old diaries. But everybody I knew was there waiting for me. Children, friends, neighbors, repair people. "Would you please all leave me alone?" I said. But they didn't. And when I woke up, I realized I had not really wanted them to. However, I also reflected that my TUP editor had not been there. Nor Jeff, nor any other man.

In very-late January I finally heard from the second reader. She did not glow like the

first reader and she had several suggestions. “What do you think?” asked the editor’s cover letter. Indeed, there was much I was thinking. I had lots of ideas as to which suggestions of hers I agreed with, which not, and why. I hoped that’s what it was a matter of. I jotted them all down in my diary. For example:

“She suggested I explain ‘conspiracy of silence’ more fully and I know just how to do that. However on page 106 I don’t feel that I’m ‘cocksure’ about the tantrums.”

“She said that well spouses also need permission to *not* express anger. Well, yes, true, but I believe that *more* well spouses need permission to express anger.

“And yes, I’ve made some more reference to and explanation of the medical stuff. And I edited a few details out of my dreams.”

“I feel she has it all wrong about the last two chapters. I think I made it clear that my questions were gropings, not literal conclusions. When I asked ‘Do I have the right to be rescued?’, I did not mean that literally. However, I did add stuff to make it even more clear, including ‘Did I have the right to ask these questions?’ “

“And about ‘she describes making phone and mail contacts without following up’ -- not true! I believe I made that clear in the manuscript but of course I could make it ever clearer. Also, though, even if it *was* true, so what? I’m not on trial here. It’s *their* professional job to ‘follow up’; it’s on them. *They* had said they’d call back.

“And about the (perhaps) larger issues of my ‘particular episodes’. That, to me, is the essence, and the vehicle, of my writing. That is my strength, what I have to offer. And that, in the past, has been what both professionals, well spouses, and bereaved parents

have admired about my writing. If I re-wrote the manuscript to accommodate the second reader, I would no longer be accommodating the first reader.”

Keeping my notes in front of me, I phoned Michael. “I already made changes in accordance with some of the second reader’s ideas,” I began and immediately, and happily, I could sense his body language, sense his relaxation. “Oh,” I felt he was thinking, “she’s cooperative. She’s not temperamental.” And *he* was cooperative, rather than temperamental. “You’re probably right,” he said a couple of times as I made my points and “Yes, that’s good. I like that,” and finally “Write me a note about the changes you intend to make and we can go ahead and send that contract.” -- WHOA! YES!

“I’ve seen several first-person accounts of illness and care giving, and what makes yours different is, it leaves the reader breathless.” YES! YAY! YIPPO!

So then I knew at least one of the differences between a mainstream press and a small press. You get really careful feedback. You get somebody who doesn’t necessarily agree with every sentence you write but who agrees with the essence of your book, who makes some changes, the right changes, who wants the writer to be open to suggestions but not necessarily take all of them. You get somebody to work with.

Over the next month I would discover that, besides differences, there are similarities. With university presses you do not get an advance. You do not get the equivalent of a publicist paid to promote only your book. And you do not get taken out to dinner at Le Bec Fin. Moreover, we had yet one more hurdle: The TUP board.

“Oh, that’s no big deal,” said the editor. “They always approve everything. Every once in a while they reject something but...” And so I worried some more. “Every once in

a while” a newborn baby dies. “Every once in a while” a 36-year-old person gets diagnosed with M.S. That phrase “every once in a while” is still, for me, a warning.

Jeff said, “Don’t worry, Mar. You’ll be fine.” Bea said “Oh, they *never* stick their necks out. They always go along with the editor.” “It’ll be fine” said Norma. So did Relli. I was collecting “It’ll be fine’s”. The more “it’ll be fine’s”, the better seemed my chances. As though they were all on the board.

But Michael had, in another phone conversation, used the phrases “consider the project” and “let you know of their decision”. My book was quite controversial, he told me. The day before he was to phone me about “the decision”, I found myself feeling sad, not only worried, as though the board had already decided against my book. In “A Grief Observed” C. S. Lewis wrote how grief feels like fear. To me, right then, fear felt like grief.

But my diary entry for that day says, merely, YES! YES! A big fat Molly Bloom YES! I had landed a “real” book, and along with that some super-closure. Marielle could say, “Something in our family worked out”. I couldn’t believe it, and still can’t.

CHAPTER III: CLOSURES AND OPENERS

In March 1995 it began to be noticeable that Jeff's M.S. was progressing. I was feeling even more heartbroken for him. I didn't know whether I still loved him, but my heart was broken in some way. The progression showed in his voice, his chest. Often he could barely muster the air to get sound out. It was not difficult to communicate with him but I could feel the effort that he needed to put in. Sometimes I'd crawl into that high bed and he'd whisper as we cuddled. He didn't usually feel tired. But he was scared and sometimes admitted it. "Why did I get sick?", then "If I get completely better, what would you like to do?" We talked about thrift-shopping together, restaurants, maybe he'd join in making supper, and play more games, like cards and Scrabble.

I ached for him. But another part of me thought, "Well, this is what I've been waiting for. Now he can't make any more phone calls having his paychecks put into his account. And we're closer to the end." For I had begun to want it all to end.

Normie, another very important well spouse friend, was feeling the same way. She was famous in the well spouse community for her joke: As chaplain of her husband's nursing home, she'd often counsel recent widows. And as she did so she'd think, "Oi, always a bridesmaid, never a bride!" Soon after I'd heard this, I had left her a phone message, "Normie, if and when you're a bride, would you please throw me the bouquet." After that Normie and I often used that as a metaphor in our conversations.

Jeff's fears were most apparent during dinner time. The aide was very patient, but Jeff kept trying that patience. A little more of this, a lot more of that. Could that last

spoonful be scooped up more thoroughly? And could the pillow be adjusted? There seemed to be no true position for it. The bed, too. “Up more -- no, down -- no, more up -- now the foot part”. Leaving-time was getting more and more poignant. “Too bad,” he’d murmur, though with a kind of dignified acceptance. Then, though, “Can you adjust the blow tube?” It had been fine five minutes before.

The doctor had told us that his loss of voice could be temporary, due to a urinary tract infection. It was also heartening to see that he still had the strength to whisper. In fact, he had more strength to whisper than we -- meaning the aides, the kids, and I -- had to *listen* to him whisper. We had to bend down, straining, putting our ears first to the right, then the left. And we had to stand up. And keep telling Devin to sssh.

“I shouldn’t have gone to Dr. Sylvester” was a common refrain of Jeff’s. Dr. Sylvester was the homeopath he’d tried, fifteen years before, soon after his diagnosis. Of course the homeopath had been unable to cure him and the M.S. had gotten worse, no matter what Dr. Sylvester did or didn’t do. Calmly, I reminded Jeff of my four miscarriages. “Remember how I kept thinking, I shouldn’t’ve this, I shouldn’t’ve that.” And all that time it was the progesterone level, *only* the progesterone level.” Jeff nodded.

“Do you have any place where he does anything besides nod?” asked TUP’s Michael.

“Well,” I had to answer. “He’s a nodder!” I was relieved that Michael laughed. For I knew, even then, that it was not a simple matter of Jeff being paralyzed; there was mental stuff too, stuff which had not been officially diagnosed so I couldn’t put in the book, especially since I’d need Jeff’s permission for it to be published. At the back of my mind,

during that period, was the worry that Michael would sense this and say that my story was too far afield, they couldn't publish it after all. "Give the reader a place to stand," he had suggested, as a way of summarizing some of the second reader's comments, and I had understood and agreed. Now I was afraid he'd wind up saying, "I can tell there's something really weird about your marriage and the whole thing makes your book invalid." In other words, I was afraid there *was* no place for the reader to stand.

The other day, riding in the car to a poetry reading with my current husband Jon and our poet friends Lili and Robert, I told them about this present book. "I'm writing a sequel to *Dirty Details*," I said, "and it's been very exciting... I want to tell the world that, even after nursing-home, it's still nightmarish for the spouse..."

Lili interrupted. "The real nightmare is for the sick person." I suppose I shouldn't have been surprised. Lili has been very supportive of everything I've done and written, but she's also felt extremely compassionate towards Jeff -- sometimes, as just then, to the extent of feeling *less* compassionate towards *me*. Or so it feels.

"Yes," I answered, "the sick person does have the real nightmare, but that doesn't mean the family doesn't have nightmare too. And --" I paused, because this was something significant, "the system looked out for Jeff. It did not look out for his family."

"Yes," Lili agreed. And you, the reader, will see more of what I meant much later on, when the "conspiracy of silence" rears its ugly head again, with hair like Medusa and snakes on its face, too.

It was indeed a urinary track infection and so Jeff's voice started coming back -- a reprieve, and a long one, as things turned out. I continued to dream about other men. Was I dreaming these dreams because I wanted to be dating, or because my friends wanted me to be dating?

The American Mathematical Monthly wrote that it was interested in using some of the poems I'd written while working on that comparability problem. Also, my teaching ratings at Temple were amazing; they couldn't have been better if I'd written them myself. "Great teacher." "Wonderful." "You can't improve on perfect." "Temple should keep teachers like Dr. Cohen happy!" I hadn't known students could write so well!

But I wished I made full time money. Then, among other things, I could take a *real* vacation once the term ended. A vacation without the kids, a place of my choosing; I'd chose New York City. Every day I could decide what I wanted to do. I could go thrifting every day and nobody would know I hadn't gone to museums. I'd leave early enough every morning to get there just as one opened, then wander from one to the other until the last one closed, stopping only for ethnic meals and snacks.

I wished you could buy house insurance at a thrift store. Or heat. Or gas. Or a "bed" in a nursing home. Or money.

In April 1995 I received a request from the I.R.S. for Form 942, 1992. It had to do with Homemakers Service, which we'd used before Jeff started living in the nursing-home; they provided us with free home health aides six hours a day, five days a week. I went into our '92 files and it wasn't there. So I called Homemakers and they couldn't find it either; they asked me to mail them the I.R.S. request. The 15th was approaching.

Also, and this was worse, the previous year Jeff had earned several thousand consulting for some company. They came to him for the consulting, we'd all been proud of him, and Jeff had rightly felt pleased. But now it was time to pay the taxes on it. And Jeff had put the money itself into an account under only his name. In other words, it was falling to *me* to pay the taxes on *his* money. Would he pay me back? If so, when?

All that would have hurt less if the Dean's Appointment the Temple chairman had tried to get for me had come through. It would have been a full time salary, one which Jeff couldn't put into his account. But the chairperson had called me into his office to tell me, regretfully, that they'd gotten only two Dean's Appointments for the next year and priority had to go to the post-docs. He'd hoped to get five which, he said, was what they usually got. I was all too familiar with "usually". "This kind of thing doesn't *usually* happen," the home health aide agency had said of the night nurse not showing up. And, from Jeff, "I'm not feeling very well today." (Like, "I *usually* feel well"...)

"Are you teaching Calc 3 next year?" my students were asking me. "I have a friend..." One student brought a friend to meet me. But none of that mattered. In August of that summer the chairman phoned me, rather upset. "Everything's completely changed around. We're not allowed to hire part timers at all." I was out of even a part time job.

Jeff and I had shared everything in our courtship and marriage. But now his mind was going. I could no longer trust him. I could love him but not trust him. So I didn't tell him my main fears, fears of his powers, to call up payroll and have his checks auto-deposited into his special account. No, I wasn't going to plant any ideas in his head. His

head wasn't a regular head. There was no convincing that head. If there were, it wouldn't be convinced *on time*. I was walking a precarious tightrope and I knew it.

Five days out of seven I was an ordinary single mother; the other two I was not a single mother at all. Increasingly when I visited Jeff I was a caregiver. Not quite nights, lifting, and toilet but suction tube, catheters, J-tube adjustments, leg-rangings, and altercations between Jeff and the nurses' aides. Usually I felt that the aides were right and I took their side. In fact, I identified with them. We had Jeff in common.

Understandably, Jeff was determined. He would not accept his lot in life. That was, in a sense, admirable, but it also translated into demanding-ness. I remember "the dremel incident". He decided that the resident podiatrist at the nursing home didn't cut his nails often enough, so he asked Arin to buy something called a "dremel". It's a tool, not meant for nail-cutting, but Jeff thought he might be able to use it for that. "Say it's for *Dr. Jeffrey Cohen*," he'd told Arin, "This way they're more likely to sell it to you."

The dremel didn't work. Jeff couldn't figure out which parts were supposed to go where. And I was the one who got to try out his various ideas. After a while I refused to. Jeff was okay with this, but he had another plan. "Call Medical Supplies. Tell them you're *Dr. Marion Cohen* calling about *Dr. Jeffrey Cohen*." That felt far too involved and I didn't want to be one of the variables, so I calmly refused. Jeff did not scream, "Mar! Mar! Mar, please!" Not that time.

I was beginning to feel as though he and I had an unwritten pact: I visit and administer to him and he not transfer his paychecks out of our joint account. Sometimes I'd look at him and think, "Which came first, his being this way or me not loving him?" I'd

trace things back, recalling incidents in our early life together, 'way before even our marriage. To some people that seems far-fetched but I had a strong hunch there was brain damage even back then. My hunch was later validated, when I found out it had been recently discovered that M.S. dementia can surface long before any other symptoms.

I had shared with Jeff my feelings of frustration over those incidents and he had understood. But it seemed he was unable to avoid them. Sometimes I'd tantrum over them and ask, "Why? WHY?" He'd look helplessly about and quietly murmur, "I don't know."

Jeff was a committed husband and father, and a brilliant physicist. But some kinds of stuff he got mixed up. Things would get complicated in his presence and take forever to untangle. These things were increasing by the number, as well as by their seriousness. But he still passed the psych-eval. He also passed it many years later, when his symptoms included the verbal and financial abuse I've alluded to. The law continued to be on his side -- or rather, not on my side, nor Devin's side, nor anybody's side.

He had rescued me from adolescent loneliness, and continued to touch me in many ways. He had, in my mother's words, "broken through my loneliness". But as I grew into a young adult, then not-so-young, I had learned to break through my own loneliness. Now I knew that, right or wrong, I would increasingly want to phase him out of my life. Sometimes, rarely, memories and old feelings emerged. Eating out in Chili's one evening with Devin, Jeff had been unusually pleasant, attentive to Devin and careful not to obsess over the food. When we'd gotten back and settled in his room, I noticed that he had something wrapped in a napkin lying on the chest, something he intended to throw out. I looked inside the napkin and found two pieces of toast left over, I assumed, from

one of his dinners. “What should I do with this?” I asked. Then I laughed. “Oh,” I said. “I see you’re still pulling no-toasters.”

At first Jeff didn’t seem to get it but then I said, “Remember the no-toasters?” and he smiled, in that way.

“What’s so funny?” Dev asked.

“Oh,” I answered. “Well, Dad always used to not like toast. I’d make toast and say ‘Want some toast?’ and Dad would say ‘No thanks’ and I’d say ‘Oh, you’re pulling a no-toaster’ again’ and we’d laugh.” Jeff and I exchanged that kind of smile again.

“What so funny about that?” Dev asked again.

“Well, it’s a little like you and the eggs. You know how you never want eggs, and I lingo ‘Come on, Dev. how ‘bout an egg?’, knowing perfectly well you won’t want it...”

“Oh,” said Dev. “The egg *yolks*,” then *he* got that smile, too. Jeff nodded and we kissed again. His lips seemed soft, tender, and I didn’t think about the teeth underneath them, how lately there was always food caught in the left back and how a couple of visits before he had, in that obsessive way, asked the person feeding him to please go into that top drawer -- no, *that* drawer -- and get the toothbrush -- no, *that* side of the drawer -- then, later, after the aide had left, there was, predictably, more food caught in there and I’d said, “I’m not brushing your teeth any more” and he said “Just put the toothbrush in my mouth” and when I did he wriggled it around in there using his jaws, looking proud that he could take care of the lodged food by himself. Minutes afterwards I’d closed my eyes as I carried that toothbrush to the sink, ran it under the water, and beat it against the side of the sink. I didn’t think about all that. I just kissed Jeff again.

And now, writing about the “no-toasters”, I laugh again, very heartily. But I recall how, at the time, on the bus ride home, I thought, Gee, I wonder whether some other man wouldn’t like toast and would pull a no-toaster and we’d laugh like that? And now, thinking of my present husband, I answer that question with another question, addressed to him, “How ‘bout some cilantro?” and I laugh just as heartily.

On May 1, 1995 a well spouse incident occurred which inflicted me with the kind of anger that hurts. I’d worked things out with respect to tantrums but happily, I had not worked out the ability to feel angry and hurt when appropriate. Jeff had to go to the hospital, once again, to have the J-tube replaced. We waited around all afternoon, from 12:00 ‘til 5:00. All they had to do was put in the new tube, take a simple X-ray, and put in one stitch. But a “trauma case” had come in, a guy shot in the chest five times. So I ranged Jeff, got him Mexican food from the truck, and adjusted various body parts.

But he also wanted me to go back with him, later, in the ambulance because he was afraid the ambulance people wouldn’t listen to what he said. I could understand that he felt safer with me; on the other hand I knew about his issues, lack of trust and exaggerated sense of risk. I felt tired and home was much closer than Inglis House. Also, I knew the kids were waiting for me. But Jeff kept mentioning it and I knew he’d probably wind up pleading, “PLEASE come back with me.” We were both tired. Still, I was hoping he’d collect himself. I was also hoping the ambulance people would be nice so Jeff would feel okay with them. Then I could just walk home, make supper, and relax.

When the ambulance arrived, I said that Jeff’s voice was very weak, could they please try extra-hard to listen to him closely. I explained that I couldn’t go back with

them. “Oh, what a shame!” said one of the guys in a weird sarcastic way. Then he said, “You should be ashamed of yourself.”

“Are you KIDDING?” I asked. He didn’t answer. “I HOPE you’re just kidding,” I continued. “I hope you understand what the families go through.” He continued to say nothing, likewise his partner. And that was when Jeff intoned, “PLEASE come with me.”

A couple of minutes later one of the doctors came up to discharge Jeff, apologize that he’d had to wait so long, and wish him well. She was great -- to him. To me not even a glance. After she’d walked a few feet away, I went up to her. “Excuse me. I have a question. An EMOTIONAL question.” She turned around.

“I... well... “ I began. “He wants me to go back with him in the ambulance. It’s a five or ten minute ride. I...” I gestured. “I know how he feels but...” I gestured some more. “I’m drained. And I have a child at home and right now I’m feeling completely confused, I’m wondering whether you could just tell me: Is it selfish of me not to go?”

“How old is the child?” she asked. Then, “I can’t tell you what to do. Why don’t you just go with him, quickly get him settled, and then go home. I’m sure your child will understand... I know how you feel; damned if you do and damned if you don’t...”

“Yes, that’s it,” I said.

“I have an eleven-year-old,” she continued, “and a sick mother and I work full time.”

“That’s your choice,” I wanted to say. “This is not my choice. Nor am I getting paid for it.” When I thought about it afterwards, and when I think about it now, I see that this doctor really did try. And I don’t feel angry. In fact, she was probably right; I probably should “just go with him, quickly get him settled, and then go home”. And indeed that’s what I

wound up doing. But when she'd said, "I can't tell you what to do," I'd felt talked down to. And I had in fact wanted her to tell me what to do, and was glad when she did.

What I did about my feelings of anger and hurt was whip "Epsilon Country" out of my bag and brandish it. "This is the book that I wrote about the subject," I said. "... I don't need a lecture. I need... right now I just need..." What I needed was for her to buy the book and love it and arrange for me to give a reading from it at one or more of the conferences that she probably went to, full of well-paid professionals who would also buy the book and arrange for me to read from it at still other conferences. Instead she only sported an amused smile. Maybe she thought it was somebody else's book. Still, I thought she should have been interested in *any* book on the subject.

Later I said to the ambulance guy, "I don't know whether or not you were kidding but you hurt me."

"I'm sorry," he said. "I was only jesting."

I should have said, "Well, don't jest in that way", but I didn't. I just didn't. When I got home, though, I reflected, "Well, I used to feel that way pretty much every day. Now that he's at Inglis House I feel that way about once a year. Thank Goodness."

In July 1995 the five of us went to Rehoboth Beach for our vacation -- Dev, his home-schooling friend Jade, Jade's mother Kim, his little sister Jasmine, and me. It was 'way too hot, and we'd foolishly chosen a non-air-conditioned cottage. I, the single one (Kim was nursing Jasmine so they were a couple.) had elected to sleep on the porch. I lay awake looking at the screen. There was a bug crawling up on it and I couldn't tell which side of the screen the bug was on. I hoped not the inside. There was

that half-second when it spread its wings, just enough for me to know it was about to take off. I watched the clear outlines of the bug become blurred. Then I saw that the screen was in front of it. Whew! It was a tiny distance from the screen but in the right direction. Yes, it made a difference that it was minus-epsilon rather than plus-epsilon away from the screen. Two epsilon was small but it mattered.

I thought about absolute value. That's what I'd be lecturing on as part of my Community College interview, two days after returning from our vacation. One reason I'd been applying for jobs was, I didn't want anyone to be able to say I was avoiding getting a job. Another reason was, there was a chance that, sometime later if not sooner, I'd really need a job; Jeff could pull some financial crap that took away *all* the money.

A few minutes later, on one of the other screens, I saw another bug and it was quickly apparent that this one was on the wrong side of the screen.

My parents had both been teachers and because of that I tended to take with a grain of salt some of the complaints that some other parents had about their kids' teachers. None of my relatives ever worked in a nursing home, but I drew the parallel; I took with a grain of salt the complaints that both residents and family members made about the Inglis House staff. And again, I identified with the staff.

But not entirely. It got back to me that some nurses aides resented family members because, they said, they "put" their relatives in a nursing home. Some aides feel superior to family members (not realizing that caregiving for pay, by choice, and only during work hours, as a professional, with the presence, help and backup of other profession-

als is very different from at-home caregiving by a family member.) So I'd go out of my way to let the aides know that I was their "comrade" in care giving. For instance, Kathy was getting ready to get Jeff up; she'd washed and dressed him and now she remarked, "I'm just waiting for Joanie to get here and help, and then we'll get you up." I said, "Take your time. I waited SEVEN YEARS for Joanie, or ANYBODY, to help." And yes, Kathy laughed. I assumed and hoped that meant she got it, that she didn't resent me.

One day Bret, now sixteen, plopped himself down on my bed to inform me that he wanted to start visiting his dad every two weeks instead of every week. He couldn't, he said, stand to see his father that way. I understood and was more than willing to allow him his feelings and choices, and I let him know that. But inside I worried, selfishly. The nurses at Inglis House might say to me, "I see your kids don't visit their father very much." As though that were *my* fault. And as though I could do anything about it.

Devin was still taking what I called "vacations from growing", especially when we visited Jeff's parents, or when I took him to the dentist and we went to Burger King afterwards. But on the bus he once said, "There's one thing that I fear the most."

"Do you want to tell me what it is?" I asked.

"No," he answered.

Maybe, I thought, he wanted me to know but didn't want to say it so I asked, "Can I guess?" He let me guess but I *didn't* guess. After a while he said, "Okay, you had your twenty questions!" But then, "Well, I want you to know but I don't want these people [on the bus] to know." Off the bus, though: "NOW I don't feel like saying it again." I still think he was flirting -- with me, with himself, with his fears and feelings, with growing

When Jeff had first entered Inglis House, one of the professionals there said to me, “The kids are angry at Jeff. And on some level, they’re probably angry at you, too.” For keeping Jeff home too long, or not long enough. For not letting them be “Oedipal winners”. For not letting them control me. For not curing their father. It felt unfair.

Before they could publish the book, TUP needed permission from all five members of my family. I was afraid they wouldn’t give it. Especially Jeff. He couldn’t write. True, he could sign checks by holding a pen in his mouth, but I thought I’d make it easier. I simply asked him whether he gave permission and when he said yes (Thank Goodness), I just signed his name for him. I thought that would be okay. But a few days later Michael phoned. “I’m sort of embarrassed to say this, but I can tell you signed Jeff’s name.”

“Oh,” I said, not missing a beat, “it’s not that he won’t sign it; it’s just hard for him to write; he’s completely paralyzed. I thought it would make matters easier if I just asked his permission. It’s not a problem; I’ll get him to sign next time I visit.” I was afraid that, next time I visited, Jeff would have changed his mind but he hadn’t (Thank Goodness).

My big poetry reading in Inglis House’s main auditorium wasn’t that big. My audience was mostly residents, who slumped and coughed and needed to be attended to and couldn’t buy books. The staff people were busy at their jobs. Yes, the ones who weren’t attending the residents at my reading were attending the residents *not* at my reading. Wherever I was, and wherever I wasn’t, residents needed to be attended to. I felt grateful that I didn’t need to be attended to but I also felt resentful that my status in life was such that I was always supposed to feel grateful.

Later it also got back to me that the assistant director had said, “Some nerve of her, wanting to be paid for her reading after all we’ve done for Jeff.” It didn’t seem fair that I was always in situations where, again, I was supposed to be grateful for something most people had -- namely, no nights, lifting, and toilet. I had as much right to no nights, lifting, and toilet as anybody else. “What about all *I’ve* done for Jeff?” I thought. *They were paid* for “all they did for Jeff”. And I hadn’t been.

Jeff had a particularly bad bout of pneumonia and the doctors were saying perhaps he shouldn’t be eating at all but getting everything, not only liquids, through the J-tube. Food was one of Jeff’s only remaining enjoyments, and he was a pretty good sport about this latest development. I recall one visit when he said some nice things. “You’ve been the perfect mother.” “You’re really nice. God’s going to reward you.” He smirked when he said that, knowing my religious beliefs, or non beliefs. I smirked back. “I’m not holding my breath on that one. I think I’ll just keep rewarding myself.” Back to Jeff: “We should’ve gone to all those restaurants.” “We should’ve gone to Florida without it being for a physics conference.” “Tomorrow when you come we’ll go over another chapter of your home-schooling book.” All that made me feel loving. But not strongly. It was as though it were all in the past. And, more and more, I wished that it was.

To help promote “Dirty Details”, I wrote an article and got it into our local paper The Forum. But just as Michael had said “The reader needs to know more about Jeff,” now the editor was saying, “I still don’t get a sense of your love for Jeff.” Part of me screamed, “This isn’t about Jeff,” and another part of me felt worried. Maybe I really *didn’t* think enough about Jeff. The Forum called the article “My Husband, My Patient”

and, once I'd revised it, put it on the front page. For months I was recognized all about town. But I had a fear, a bad fantasy: newspaper reporter or TV talk-show host suddenly stands up and points a finger at me. "I can tell," he booms, "that you don't care a whit about Jeff. All you care about is that book." There would be a lot of truth in that, understandable truth. While you're writing, and publishing and interviewing, you sort of forget about the thing itself. Or the nightmare presents in a different, perhaps refreshing, way.

"Ya know," I answered, about all those restaurants Jeff had said we should've gone to, "they have a bunch of new ones in Philly, around 2nd and South. There's one that's sort of like the Pompeian..." I was referring to that place in Greenwich Village, when I was going to N.Y.U. It had looked like a little castle, all those white lights. Jeff remembered the Pompeian and he nodded. Then he said, "Pick one out."

I knew that was truly lovely; I touched his cheek, kissed him, and said, "That's what I've always wanted. I wanted you to say that, to feel that. You don't actually have to take me to that restaurant. You said you wanted to and that's enough."

On yet another good day he began leveling with me, and with himself. "I've *always* felt sick. I've always felt something was wrong. Weight-lifting, dates in the car 'til 4:00 AM, too much sex -- it was all to make it seem like I was healthy, wasn't tired."

"This is good," I thought. "Our romance is ending well." Perhaps I could fall in love with him again. But mostly I thought about his deathbed. If he continued to be honest like this, it could be a good deathbed. Yes, I thought, I bet when it's a good deathbed

you come away from it glowing, like after a good date. There's the first date and there's the last date. And they're both ... well, dates.

Writer-wise, I was getting what I'd wanted and hoped for from "Dirty Details", namely the mainstream author treatment. I read at the Philadelphia Ethical Society, Organization of University Women, several M.S. support group meetings and workshops, our local library, a Wages for Housework conference (I called my talk "Wages for Care Giving"), and many Borders and Barnes & Nobles. The library reading led to the formation of a new well spouse support group. Sometimes it felt weird; after all, I had written and was now doing readings and interviews about a very sad thing that had happened to me and to mine. And here I was, feeling happy. I was having a great time. Did I at least feel guilty? some might ask and I'm afraid, or rather glad, that the answer is no.

I was on Radio Times and several other radio programs, as well as a TV program. The book got twenty or more reviews, all positive except for Kirkus, who felt I was selfish. (They didn't say anything about the quality of the writing.) The Star Ledger, which had recently done an article about Jeff, now ran one on me. Over the next two-or-so years, there were reviews in the Washington Post, the Philadelphia Inquirer, and some smaller papers. Of course, TUP sent a copy to the New York Times, but that paper didn't review it; to this day one of my unrealized dreams is to be reviewed by the Times.

One high point was a reading at the Philadelphia Borders. I had worked hard to get it, having had trouble locating who was in charge of scheduling. But now I was to read with John Thorndike, author of "The Long Way Home", about raising his son amidst his ex-wife's creeping insanity. "I see you brought in the local scene for me!" John remarked

about the huge crowd that had assembled and was still assembling. Family and friends -- Relli writing friend, Phyllis singing partner, Kathy soul sister, Karen and Monique from Feminist Scrabble Club, Rita from Well Spouse, Carol and Gret from choral group, Gail from Inglis House, a woman whom I'd met the previous day at an Indian restaurant -- I surveyed them all, scattered among the much larger set of unknown faces. And here was Devin, now aged ten, sitting on my lap just before I was to go on "stage". Marielle later told me that, as the reading was piped over the intercom, people in the store stopped shopping and came on over. It was a standing-room-only crowd; I'd estimate 80. Moreover, the crowd was attentive. Their eyes stayed. Their body language stayed. And *they* stayed; nobody wandered off. They laughed when I'd thought they'd laugh and looked pained when I'd intended that. "How non-Kafkaesque!" I thought.

John, the other reader, was just as interesting and successful; during both our readings we kept glancing at each other and giving encouraging nods and smiles. Afterwards there were plenty of questions. "This is great," I thought, "and it's going to get greater. People are going to be lining up for me to sign their books, then we'll have dinner out, maybe with the other author, maybe he and I will connect romantically or at least as writers. Yes, tonight I'm going to lie awake feeling very happy and satisfied."

Then reading became signing. Audience became potential customers. John walked to the right to stand alongside his book. I walked to the left to stand alongside mine. That's when things turned Kafkaesque. I saw that most people were walking to the right. "Oh, no," I actually murmured to myself, under my breath. "No, no. This can't be." After a while people came on over to me too but neither line was very long. They were mere

line *segments*. I could *count* my line segment. Four. 80 at the reading and four at the signing. True, many people had already bought the book. And, as the years passed, I would run into people who would say they'd read my book, they'd bought it at "that Borders reading". I guessed they just hadn't stood in line for me to sign it.

Afterwards a bunch of us went out to dinner at Hoolihan's; we'd asked John and his friends to join us but they had to be somewhere else. So much for budding romance or writer friendship. I sat next to Marielle and whispered to her how profoundly disappointed I felt. "Why are you concentrating on the negative?" Marielle asked. "You just had a great reading at Borders. Is the whole purpose of a reading to sell books?"

Well, yes. At any rate it was a huge part of what I'd wanted and expected. In particular, I'd wanted that line. Thinking about it now, I realize that possibly Marielle also felt heartbroken, too heartbroken to accept. It seemed to me that, while people wanted my book to exist, they didn't want to pay for it. "Thank you for writing it," I was told. "It's sooo important." I guessed they wanted the book to be out in the world, but not in their living rooms. Something like, during the civil rights movement and afterwards, people wanted blacks integrated into their town but not into their own families. The message I got was "You're a great *volunteer*. Volunteer caregiver and volunteer writer. You're not great enough to be paid." It was only a line. But I felt cheated out of it.

"I don't really like it either here *or* at Inglis House," Jeff told me, during one of his many hospital stays. I felt bad.

"But if you came back home," I said, "I wouldn't be as nice as I am now."

“I know,” he answered, “but it would still be you.” That moved me, but a part of me was getting bored with the whole business. It was as though I were watching a movie in which I knew what was coming next; “let’s get to the end already.” After every visit, as soon as I was out of his sight, I’d literally run outside and embrace the air. Embrace my non-paralysis and my space, space that was mine to move around in. I’d embrace the street, the bus, my porch steps, the food in the fridge, all of my healthy life. I was reclaiming and that was not at all difficult to do.

What if he did suddenly get better? I sometimes thought. What if he suddenly simply walked into the room, a moving rather than unmoving object? Would I feel like the woman in Kate Chopin’s famous story; she hears that her husband died in an accident and at first she grieves but then she starts getting used to the idea of his not being around. Then suddenly he walks into the room -- he didn’t die after all -- and she dies of shock. Is that what I’d do if Jeff suddenly became a walking-around husband?

When he seemed to be suffering, like when he’d ask in that plaintive voice to have his position changed, I sometimes couldn’t help but think, “Well, that’s what you get for that advance directive.” The one where he specified that he wanted to be kept alive by any means necessary for as long as possible. The one that caused untold suffering for the kids and me, and him, for eight more years. “What if, in order to stay alive, you had to have blood gas continually?” I asked. He was allergic to novocaine. “Yes,” he answered. That advance directive was against my own wishes. It was not *my* advance directive but it did direct a huge part of the advancing, or retreating, of my own life.

In June of 1996 he complained of feeling thirsty. Usually he said, "The feeding tube makes me feel as though I've just drunk a fresh glass of water." But not lately. He kept asking them to add more and more water to the bag; the doctor said he was getting bloated. I could see what was coming. He'd want more and more water; eventually they'd have to say no. Then he'd tell me they were mistreating him. I understood that dance but none of his friends did, nor did our older kids. I felt as though everybody was trying to get me to "advocate" -- advocate for things I didn't believe in. Let *them* advocate, I thought. "YOU call the doctor," I'd say.

Bret was finding it harder and harder to visit "Dad", even just once a week. "He's being kept alive artificially," he said, "and I can't understand half the things he says."

"I'd like it if you came to see me more," Jeff said to him. "Why don't you?"

At first Bret hung his head but later he offered, "It's really hard for me to come here."

"Why?" asked Jeff. Later I explained to Bret, "Dad doesn't want to admit that he and his life are such that it's hard for a kid to deal with it."

Marielle was often nervous. Understandably. I realize that more than I did then. As our oldest she must have felt tremendous responsibility, even though I, and often Jeff too, tried to make her not feel that way. She seemed to need to be assured of things. And sometimes, in her plight, she'd turn to Jeff for reassurance, which seemed the least likely place to get it. "Are they going to be able to manage your suction tube at Inglis House?" she'd ask him or, during his many hospital stays, "Are you sure it's a good idea to go back tomorrow?" And she'd react too strongly, I felt, to his complaints about the staff. "Oh my God! Really? That's terrible!" And I'd thought she understood. When I

mentioned that to her she answered, “Well, I don’t want to discount what he tells me. I want to listen to him.” I felt that her listening to him took something from her listening to *me*. Also, I was a little nervous about what she’d learn from listening to him; would it be something that would make my life even more complicated? In general, I’m thinking now, perhaps *my* needs took from my allowing *her* to feel nervous.

CHAPTER IV: WELL-SPOUSE AUTHOR ISSUES

In and out of “Dirty Details” I didn’t hide the fact that I was not only relieved but happy that Jeff lived in the nursing home and I no longer had to do nights, lifting, and toilet. I’d point interviewers to the chapter “Chronic Grief”, how it’s something we don’t quite feel. “I want to make it clear,” I’d sometimes say. “I’m *not* sad. This book is about something sad, in particular sad for him, but *I’m* not sad. I still have a long life to live and I’m happy that I can live it. I couldn’t before.”

I enjoyed the promotion of my book and wanted more and more of it. One day, during a week when there was too much of a lull, I got in the mail a card from one of the caregivers associations. On the cover were flowers and inside was the printed out message: “You are loved. You are appreciated. Consider yourself hugged.” But what I’d been waiting for from that very association was a response to my query about their reviewing my book. And so I felt loved, appreciated, and hugged in too general a way.

Jeff’s father had had a stroke. That was in addition to Parkinson’s. Jeff’s mom was insisting on keeping him home. True, they didn’t have the same trouble with home health aids that we’d had. But still she, in her 70’s, was doing toilet and some lifting. I tried to get her to consider nursing home but no, she said, she wanted to see this through to the end. Marielle and I sensed that she didn’t *truly* want to. “I think she doesn’t want to be the one to suggest it,” Marielle said. “She wants the professionals to suggest it.” That sounded quite familiar. Jeff’s mom had read Dirty Details and said, “It gave me some things to think about.” But nothing had come of such thinking, not even

when I said, “Devin needs a Grandma. You’re the only Grandma he has.” We heard increasingly from her doctors that she seemed disoriented. Close as I was with her, I made it a point not to get more involved in that than I wanted to be.

One day during a slow week for “Dirty Details”, and a moment when I was letting it get to me, the phone rang. “Please oh please,” I said aloud. “Please don’t be Jeff. Please not something downtrodden.” But it was Jeff. When I hung up, I checked my messages. As I punched in the appropriate code for Answer Call, I smirked, “These can’t be Jeff. He’s the one I’ve been talking to all this time.” But all three of them were. “Oh yeah,” I conceded. “I forgot to erase that one.” And about the other two, “Oh yeah, there’s a backlog.” It was all very logical but the underlying message was, you can’t escape downtrodden by talking with downtrodden.

One day I got yet another phone message from Inglis House about the J-tube coming loose. This time I did something nervy: I pretended to not have gotten it. “I pull that all the time,” Normie had once said to me. “and it works. They can take care of that ol’ J-tube by themselves; they don’t need YOU.” We had laughed about it then, and I laugh right now, over ten years later. I also feel the same sadness.

Sometimes, after being suctioned, Jeff would say, “There’s something on the roof of my mouth.” I’d try to aim the suction tube upwards, would try and try. Sometimes the suction tube wasn’t enough. That meant paper towels in his mouth, again and again until he was satisfied. The head nurse said he “had control issues” and I knew she was right. But, in the throes of each individual circumstance, was control what it was a matter of? Or was he actually horribly uncomfortable?

One visiting day another resident needed my help. “Just one more thing,” she kept saying, and when I had done that, “and then...” Jeff was always saying “and then”. Besides, this woman’s “and-then” was “put those sunflower seeds in my mouth”.

“I’m sorry,” I said, “but I don’t do things like that.”

“Why not?” she asked.

“I just don’t feel comfortable with it,” I answered, “and I don’t want to take the responsibility.” I watched and heard her electric wheelchair buzz away, feeling the same sadness of limitation that I felt when I refused something to Jeff.

At one of the well spouse workshops the term “caregiving for a loved one” was mentioned. Realizing how often that term is used by professionals and in hospital brochures, I bristled inside, then stood up and said evenly, “I don’t like that term; it seems presumptuous. I don’t think the care receiver is always a ‘loved one’. Many of us here do NOT love our care receivers; we might care, act responsibly, and have all sorts of complicated feelings, but love? When a well spouse hears that term, she might feel guilty and think ‘What’s wrong with me, that I don’t consider my care receiver a loved one?’ ”

A few months later I got a phone call from the editor of the Well Spouse Newsletter. “I like what you said at the conference about the term ‘loved one’. Would you like to write something up for the newsletter?” It went on the front page, under their title “End-stage Relationships”; the last sentence was: “Perhaps for the purposes of hospital... hand-outs, the patient is simply ‘the patient’. Only we know the rest of the story.” My view was shared by many but to this day I have not noticed any decrease, among either professionals or well spouses, in the use of the inaccurate term “loved one”.

Another piece of activism: I suggested to the Family Members Support Group at Inglis House that we initiate an event in honor of family members. “They have events honoring nurses and volunteers. *We do just as much, maybe more.*” The group agreed and I wrote up the proposal. Here it is, in part: “At Inglis House, as at many other skilled care facilities, there have often been special events... to honor nurses, volunteers, and so on. We would like to propose a similar event to honor the family members, friends, and ‘significant others’ of our residents... These are the people who brought our residents to Inglis House in the first place, who took care of them *before* they came to Inglis House, who perhaps struggled to *keep* taking care of them and not have to bring them to Inglis House.... We all have our stories. Many simultaneously raised young children, worked full time jobs or built up careers, and/or had more than one chronically ill or disabled care-recipient in our lives... We have all struggled with myriad and... conflicting emotions... Making the decision to have our residents live at Inglis House was not easy. ...We had to make emotional adjustments ...it’s hard to relinquish responsibility... and re-define our roles in life, and our relationships with our residents, with the other people in our lives -- and with our selves...By forming the Family Member Support Group, Inglis House has already demonstrated that it cares about family members. We hope it will extend this caring [in the form of this ‘testimonial event’].”

The facilitators of the group communicated this to those in charge. But nothing ever came of it. It was not actually rejected, just put on hold. More conspiracy of silence.

In my readings and lectures promoting *Dirty Details*, I was careful to go gently. I tried not to alienate people who might be upset by the idea of “putting” one’s spouse in a

nursing home. But in fact the questions people asked put me on my toes with respect to quite the opposite issue: “Why did you wait so long?”

I still get asked that question sometimes. I have several answers. First: Like a child or student, I’d been looking, consciously and unconsciously, for hints, guidelines. I had not needed to be guided by professionals to make the decisions to breast-feed, home-school, or be a woman-mathematician. But I had needed professionals to help me make the nursing-home decision. At least I needed that for *a while*-- for “so long”. Second: One can’t fight the battle, or the war, on all fronts. I was too busy fighting the battle of nights, lifting, and toilet -- and finding home health aides -- to fight “the nursing-home decision” battle. Oppressed people of all sorts often can’t fight their own battles, at least not for a while (not for “so long”). They’re too busy staying alive. Third: One reason I avoided “the nursing-home decision” was, I sensed how difficult *implementing* that decision would be. I knew that, after I “just said no”, I would have to keep on saying no; saying no is not tantamount to doing no. Fourth, and bottom-line, I’d answer that question with another question: “Well, why does ANY abused person stay abused for ‘so long’?” The answers vary and one of them is, it takes us “so long” to realize we’re abused, to call it abuse.

Dirty Details was mostly a memoir -- “almost a novel”, some readers said -- so a lot of my actual beliefs were left out. But at readings, lectures, interviews, and media appearances, I made them very clear: What was at fault was not Jeff, not individual doctors or social workers, not nursing-home administrators, but society and its mindsets. (I

had *suggestions* for individual health-care workers, but my thesis was that these suggestions could be taken only in limited ways.)

Some of my thoughts not expressed in *Dirty Details* were about Medicaid. Many well spouses said that Medicaid did not impoverish them and even very radical people whom I met at political meetings said about Medicaid, “This time the system really did get it right.” But I wasn’t sure. Yes, Medicaid is rather socialistic; it doesn’t take away from you what you need, only the extras (like a second home). But I also remembered what my Marxist parents (and Marx) had said: it’s not socialism unless the *entire* society lives by it. And in the United States people on Medicaid live in a society in which *most* people with second homes don’t have to give them up, only those with family members who have to live in nursing homes. Socialism says, “From each according to our capabilities, to each according to our needs”. But how are people with relatives in nursing homes more capable and less needy? In fact, it’s quite the opposite. People with relatives in nursing homes, who’ve been through loss and dire straits, need to give *less*, and to get *more*. We need, in other words, affirmative action, not the opposite.

Promoting *Dirty Details* also brought up feminist issues. How did the well spouse community connect with the feminist/humanist movement? At well spouse meetings and workshops these issues had already come up. In my lectures I made them come up even more. “All women are in danger of becoming care givers,” I said. I analyzed the question, often put to care givers (whether women or not), “When was the last time you did something for Your Self?” People often lay that guilt trip on us. We’re accused of victimizing, enabling, not doing Things For Our Selves. It’s a case of blaming the victim.

On the other hand, society didn't seem to want us to *advocate* For Ourselves. On the same page as a review of Dirty Details was a review of a book about torture and war. "Riveting," that review said. "Amazing." But I, in an otherwise positive review, was dubbed "overbearing" and the dire straits I described "not for the faint-hearted". Was the difference gender? Or did society feel uncomfortable with the home front being "riveting"? "Society doesn't want people to advocate for *themselves*." Yet often "themselves" are the only ones who will do such advocating.

This book, too, is a memoir. But these beliefs are among the memories.

One of my well spouse friends told me that, after my Borders reading, somebody said to her, "She seems like an angry woman." And the editor of an M.S. magazine told me that she'd gotten into a little trouble because she'd put in one of my poems and a Dirty Details excerpt. They'd received some angry letters and her boss had said, "I do like the stuff -- and it's all true - but what will readers say? What about people who aren't ready for it?" "What about people who *are* ready for it?" she had responded to her boss, and I felt proud of her -- and of me. I recalled how Michael, my Dirty Details editor, had told me, "You're saying things that people don't want to hear."

Next reading, I vowed, I'm going to say, right off, something like "I realize that some people might be expecting a romantic story. And in fact it is, though in a complicated way." I might go on to read a love poem, or say that at this stage of the game I sometimes loved my husband and sometimes didn't, and that this was due in part to his unpredictable behavior and in part to my own musings about where my own life (in particular, romantic life) was going. Some people, I knew, would be "ready" to hear that and

some wouldn't be. And maybe those who weren't ready would hold it in storage for when they *were* ready. At any rate, I thought, ready or not, here I gently come.

Another high point in the Dirty Details publicity was the Radio Times interview. The host, substituting for Marty Moss-Cowaine, did a wonderful job; her support and enthusiasm came through loud and clear. The people who called in, including Normie, were equally supportive. There was one "jerk", as Marielle put it, a male nurse who said, "It seems as though she's complaining; she has a 'Why me?' attitude." I was glad for the opportunity to get across yet another important idea. But the moderator couldn't resist the first crack. "I'm not supposed to do that," she told me later. "I couldn't help it." What she said was, "She's not complaining. She's simply telling it like it is." Then I jumped in. "I'm not asking 'why *me*?'. I'm asking 'why *us*?' Why all caregivers?"

In the halls of Inglis House wheelchairs passed and buzzed like big flies. Jeff was annoyed by it, too. "'Round and 'round," he told me. "'Round and 'round they go. That's what they do all day long. Go 'round and 'round.'" There were so many activities available for the residents, but they still spent most of their time going 'round and 'round.

Jeff was requiring more pillows. Three, four, to fill the spaces, make enough cushioning. And he was still always needing them adjusted. "Further away from my neck." They weren't all pillows; some were pillow cases stuffed with blankets. Actual pillows would take up too much space. Still, "fluff them first". Dev and I would, right or wrong, get hysterical. "How can you *fluff* a flat pillow? It's like fluffing a pancake without baking soda or rising a cake without yeast -- yeah, like fluffing matzoh on Passover." I'd get a little

giddy. “Devin, would you please go fluff that table? Would you please go fluff that wall?”
Jeff did not join in the laughing so we stopped.

No possibility of fluffing his HAIR, either. Nature had given him gorgeous thick black curls but he wanted them as short as possible. Dying people often slow down their appetites. Jeff was doing the opposite; the closer to dying, the more food he wanted. Still, there were other things he was phasing out, and one of them was his bounteous hair.

In July of 1996 I wrote Hillary Clinton a letter: “If we want our chronically ill and/or disabled citizens to be first-class citizens, and their spouses and children to truly be able to love and respect them and not view them as burdens, then we have got to have 24-hour fully-funded at-home care.” My well spouse friend Marilyn also wrote to Hillary. We both got back the same form letter: “Thank you for writing to me. I appreciate that you took the time to share... your ideas.... The President and I welcome....”

As a joke, Marilyn and I made up parodies of responses we might have received. I’ll tell you hers first, in part: “Dear Marion: Your letter arrived today. The prez and I were so delighted to hear from you. You light up our lives. We shall tell Chelsea all about you. Perhaps you can teach her the ropes of thrift shopping. And the perfectly marvelous way you have managed to bring fine-tuning to care giving. We are so proud of you. And we are also proud of the fact that we never hadda do it. For people in privileged circumstances *there are no dirty details*. We don’t know from shit cleaning... But we do know how the common folk want to get close to us. What burdens we carry, we elected officials... Bill and I feel that being a full time caregiver definitely makes you a better person... Sincerely, Hillary Rotten Clinton”

Mine was more wishful parodying: "Dear Dr. Cohen: Thank you so much for writing to me. I love your writing. You can write to me any time you want, and I'll publish it. Moreover, I'll send it to everybody on my mailing list (in particular, Marilyn) I'll personally see to it that all your suggestions are taken. With utmost reverence, your ardent fan, Hillary. P.S. Sorry this isn't typed. I'm on the train en route to thrifting. Ya think I don't thrift?"

Well spouse humor is the humor of the oppressed.

I often went through periods of feeling heightened guilt for not teaching full time, not having ever taught full time, except for that one semester being assistant mathprof at C.C.N.Y. The reasons for not having worked full time were several, most of them valid and healthy: I'd been busy mothering and care giving; I was a writer; I hadn't published many math papers; my thesis advisor lived in France. It wasn't my fault, I kept telling myself. I didn't have psychological hangups, in particular "fear of success".

I have never, in my entire life, taken fitting in for granted. Having a family, a home, jobs, friends, talking with people on the streets -- maybe that last comes from my adolescent stuttering; I always feel grateful that I can talk. Just like I feel grateful to no longer be doing nights, lifting, and toilet.

At age 53, I still had only three or four grey hairs. The rest of my hair still shone golden-reddish in the sunlight. I had energy, could walk ad infinitum, and had high cheekbones. But in the mirror there was something. Not wrinkles, not sagging. Perhaps a sort of pulling. Around the lips, maybe. Maybe this was just a bad-lip day.

I was losing my husband, my children, and eventually my body. I was afraid I was also losing my soul. Afraid I'd stop writing, wouldn't be able to do math or understand the math I was supposed to teach, wouldn't be able to feel the wonder of things, would even forget about my babies. One morning I felt lonely and wanted to talk with Jeff. But when I called he had essentially no voice. Sometimes it was okay if only I talked but that time it wasn't. "I just wanted to hear your voice," I said. "I felt lonely, I wanted to talk WITH you, not only TO you." He stayed on the phone, but I still felt lonely.

I went to give a Dirty Details reading at the Jenkintown Barnes and Noble, and nobody came. "Well, it was snowing," said Marielle. But that had been the previous day. And the store itself had been well populated. It happens to most writers but it was still sobering. I realized anew that I'd never be able to make a living as a writer. I wished I was a celebrity like Hillary. I bet Barnes and Noble wouldn't *let* nobody show for *her*. If She'd written Dirty Details, it would be a best seller. She'd make plenty of money on it and everybody would talk about how she didn't just suck up to her husband but did her own things and made her own money.

How jealous I was of Hillary! But then something nice happened. During my next visit to Jeff, although he wasn't feeling well -- over-heated and no voice -- he mouthed to me, "How are you?" and when I told him how no one had come to my reading he mouthed, "I'd've come. If I were healthy, I'd've come and recorded it."

In January of '96 he told me that it wasn't the long ago days, when he was healthy, that seemed unreal, but these days, now. He also said that being paralyzed felt like he was tied up. I had been hoping he wouldn't say that. Still, much as I felt for him, I also,

right or wrong, got increasingly annoyed when, upon my arrival each time at Inglis House, the aides would exclaim to Jeff things like “Hey, Jeff! You’re WIFE’s here!” “Lookit the smile on his face -- that’s ‘cause his WIFE’s here.” “How’dja get such a pretty WIFE?” “I know why he’s got that big smile on his face -- it’s ‘cause his WIFE just walked in.” “Hey, Je-eff. Guess who’s here? Your WIFE. ” It was enough to make me want to not be pretty, not be wife, and not be here.

“All that’s for Jeff’s sake, not yours,” said Freda when I told her about it. Indeed.

When you’re a writer who writes about “life stuff” -- well spouse, pregnancy loss... -- the life-stuff movement (Well Spouse Association, SHARE) has every good intention. It adores your writing, stands in awe of you. But it’s not professional. It doesn’t know that writers need to be paid for doing readings or writing articles, or else they do know but don’t have the money. Also, when their newsletters print your poems or articles, they often don’t mention your books. Or, sometimes, your name. And when some big-deal newspaper contacts them because they’re doing an article about the life-stuff, and asks for names and contact info of life-stuff people, they often don’t give *your* name. Is it that they know the newspaper is looking for *typical* life-stuff people, not authors with books to promote, and not people with non-typical opinions. They’re looking for just-plain people who can be interviewed and will simply tell their story, or tell their story simply. And I don’t tell my story simply.

CHAPTER V: LIFE-STUFF IN AND OUT OF INGLIS HOUSE

Jeff's friend and colleague Ron Geautreau arranged for him and his physics to be written up in the Star Ledger. Reporters and photographers came into his room at Inglis House, and Jeff was excited. A couple of weeks later, as Dev and I walked in for a visit, he gestured with his chin toward the top of the dresser on the right, smiling and gasping (since his voice, again, wasn't at its best), "Top of the pile -- article".

The title was "While a Body Wastes Away, the Mind Soars through the Stars." "Jeffrey Cohen lies on his back in an unlit room... Only recently has he begun to lose his voice. This is not a good sign." Moreover, some of his quirks were mentioned, such as "There are four clocks in his room". But Jeff was pleased. He would, I knew, have preferred it be like the old days when not quite as much article space was taken up by how his "body wastes away", and when family, friends, and acquaintances were admiring. When his mother wasn't all upset, when she didn't tell us, "Everyone's been calling me up and saying 'WHAT's this about Jeffrey? Is his condition really that bad?' When she did not express the wish that his father not see the article. Some of the Inglis House staff were also upset. "Your room is NOT small and cramped." Poor Jeff.

Other Inglis House Family Member Support Group members seemed much more willing than I to be martyrs, and they weren't authors of books about not being martyrs. I wanted to continue going to meetings but I wasn't always sure how to act. To what extent should I talk about anything related to my books? Was I already talking about them

too much? Or, more likely, was I bending over backwards to not talk about them too much? When people acted disinterested, and didn't buy my book, did that mean they were jealous? Should I be feeling angry or hurt, or should I chock it up to human nature and the human condition? I'd been asked to do a reading for that group and I had trouble choosing poems to read. The trouble was, it was not a question of how I felt about having a husband in a nursing home but how I felt about not being an at-home caregiver. And the answer to that question was, absolutely great. Perhaps too great for that particular group.

One woman told me, "I can't really relate to your poetry. All I can think of is, why did such a horrible thing happen to my daughter?" Sometimes I wondered why it wasn't true that all I could think of was "Why did such a horrible thing happen to my husband?" But I knew the reason: there were so many other things to think of.

I was in the same boat with respect to my book that Jeff was with respect to his newspaper article. We both wanted family, friends, and fans to congratulate us and rejoice. But the very subject matter seemed to preclude that. Instead of talking about how great it was that we had the book and the article, they talked about how "sad" the subject matter was. Or they said nothing. Sometimes I felt as though books and articles were all we got out of it, and people wouldn't let us have even that.

My Epsilon Country publisher Roberta said, "I can't imagine how you got through those years, how you survived the way you did."

I answered "I had so many WONDERFUL things; that's how I did it."

"Yes," she said, "but you were able to KEEP SIGHT of the wonderful things. That's

why I publish your books, out of my own money -- as a tribute to your courage. But,” and she paused significantly, “I wouldn’t publish you if you weren’t an artist.” Despite my other successes and validations, that felt good.

The first time I ever got the nerve to publish, I was a junior in high school. It was a self-publication; the venue was my homeroom desk. “Joe H. and Marion M.”, I carved, and on my math class desk, “J. Hemberger and M. Deutsche.” I was going for broke. -- very willing to “take risks”, as poets say. So great was my crush on Joe that I felt no shame. I kept on publishing until Scope’s gossip column contained the short question, “Will Marion D. and Joe H. ever get together?” And then until Joe’s friend Nick told me that Joe liked me as a friend.

Suppose, instead of carving on the school desks, I had actually faced Joe? Would he have told me no, right then and there? Or said he was busy, he’d get back to me? And then not gotten back to me? How long would I have waited before realizing he wasn’t getting back to me? And would I have wondered, “Perhaps I should face him again”?

Publishing and promoting is a bit like that. “You have to be a pest” was the advice I got from other writers, about dealing with the media. So, did being a pest mean call, or face, them five times? Ten? How many instances of silence really did mean no?

Ah, but the times, the one time out of ten that they said yes! Also, one of the deciding factors, decades before, in Jeff and me finally “getting together” had been a letter I’d written him -- a letter I’d “published”, in a special editor of two! Also, Jon and I emailed for two weeks before meeting; writing got us so well acquainted that the rest of it took very little time! Yes, I’ve learned that I have much to gain by writing and “publishing”.

At the Family Member Support Group reading someone asked, “Why write about it? There’s nothing that can be done about it?” One answer is: But there is. *Dirty Details* was written, not only to validate the feelings of other well spouses, but to try to do my part in changing the health care system and society. (And this book is being written for the same reasons.) But another answer to her question is: Because it’s there. Like Mt. Everest. It’s there, to climb. Another answer, gentler but less accurate, is: I don’t know.

One of the aides at Inglis House kept wanting me to *give* her a copy of my book. “Marion, after all I’ve done for you and Jeffrey...” *Everybody* in those days had done things for “you and Jeffrey”. I owed everybody. If I gave a copy of my book to everybody I owed, where would my customers come from? Where would my writing career come from? Where would *me* come from? Did I “owe my soul / to the company’s store”? Would I ever stop owing?

There was to be an Inglis House wedding, a huge affair. Robbie and Priscilla were getting married. Both had C.P. Robbie had fewer disabilities than she did. They were often seen in the hallways, he in his wheelchair grabbing hold of hers, pushing or pulling it along. She couldn’t talk at all, he barely. But he would try, and if he tried hard enough, and if the consonants were right, I could understand him. He kept telling me he wanted to buy my book. He mentioned it several times, sometimes going into Jeff’s room to talk with him about it. I knew he didn’t have the money.

I was moved by Robbie and Prissy, but I also had my usual surreal feelings. I was sick and tired of the whole “disability bit”, everybody being so damned positive about it

all, pretending it was okay and wonderful, not acknowledging the nightmare. Those surreal feelings, though, were put aside at the actual wedding. I was enthralled. There were tears in my eyes. Priscilla was dressed in an all-lace dress, soft lace, which someone told me was given to her by Resources for Living Independently. Sure, she and the dress were slumped over in the chair, but it was still soft and white. One of the other residents was the maid of honor, dressed in pink, and the bridesmaid was another resident who was very withered and whose tongue stuck out. Scott, the chaplain, did a great job in performing the ceremony. Without being too invasive, he acknowledged their situation, their joy and their pain. He told us how the two of them had spent lots of time “in my office” talking about what marriage means, in particular when it can’t possibly be consummated. Robbie said “I do” very loudly, and everyone laughed. All of Inglis House was there; they probably had more wedding guests than most couples. Scott helped them hold hands and somebody helped him help them kiss. It really did feel like an “Inglis House family”. Prissy got all her food from a feeding tube, but Kevin, the Inglis House director, fed Robbie punch and wedding cake. There were speeches and toasts; everybody made the wedding as wonderful -- and as long -- as they possibly could. Scott made sure there was a receiving line, and Jeff and I joined it.

Later, though, we ran into Robbie and he was alone. Later still I saw him in his room, alone except for the aide feeding him dinner. I hoped she was one of the nice ones, one of his favorites, and I hoped she was making conversation about the wedding. Several doors down Prissy sat alone in her room, not even eating, her bridal gown hanging on the door. The wedding was over and there would be no honeymoon. As a wedding pre-

sent, I had given them a copy of my book and Robbie thanked me, loudly, clearly, and sweetly. To this day I don't know whether or not he was able to read it.

Jeff was beginning to revert. He and his meddling friend (whom I called Lurch, from *The Addams Family*) concocted a diet which included something called Edensoy and which cost \$50 a week. In Jeff's room were stacks and stacks of this Edensoy. It was their firm belief that this diet could cure him. Jeff also developed the practice of spitting instead of swallowing. That way, he told me, he wouldn't aspirate. He'd spit into a towel and I'd then wipe his mouth. I wondered what happened when I wasn't there.

He had gotten his new wheelchair, a "sip 'n' puff", meaning he could now use his breath to steer it (since his fingers weren't working). That wheelchair took some time to learn to use and he still would easily bump into things, so they wisely put it on slow speed. Of course, that was frustrating for him, and for me when I walked alongside him.

But independent of any of that, he was back to denial and demanding-ness. "Jeff," I once calmly said, "here's what I want from you: I don't know whether it's what *you* want, nor whether you can muster it, but I want what we were doing recently, before this Edensoy craziness, I want us to face this together, what's happening, and talk about it -- not all the time but some of the time -- and to love each other through it--"

"Through WHAT?" he asked. "What's happening?"

"Your disease," I answered. "What's happening is the progression of your disease."

He looked blank. I still agreed with what I'd said in *Dirty Details*, how denial is sometimes the best way to express something. But only sometimes, not all the time. Perhaps

I was asking too much from him, but it was what I needed. Other well spouses had gotten it from their ill spouses. Later that week Gail warned me that Jeff and Lurch (as I called him) were cooking up something involving a \$1,500 shower chair.

Five years before, Roberta had remarked, "One thing you haven't yet expressed is: Why doesn't he die already?" "That's because I don't feel that way," I had answered. But now I was feeling that way. "I hope he dies soon," I wrote in my diary, mentioning also my hesitancy, though not guilt, to write that.

During the last week of August 1996, Marielle and her husband Matt came to visit Jeff the same time I did because, they said, they had something wonderful to tell us. We were going to be grandparents! I jumped up and kissed them. Jeff, of course, couldn't.

On August 30, Jeff's birthday, I dreamt that I was dating a man. I knew we would fall in love and get married. We met in an alley, not a dark alley but a light alley. When he first saw me he said, by mistake, "Hi, honey." He started to apologize but I said, "Oh, that's okay," with what I hoped was just the right look. "Yes," I kept thinking, "this is the way. I can do it. It's easy." When I woke up my main memory of the dream was the part where I'd thought, "this is the way." Yes, I was beginning to know the way.

Elle's pregnancy proceeded. But Jeff's mother didn't seem happy. Spousal care giving seemed to be draining her strength, as well as her spirit and mind. One day Devin and I were due to visit her for the weekend. We always looked forward to these visits and so did she; Grandma's house was a fun and a safe place to be. This time the plan was, we would arrive rather late in the evening since I would be detouring at the Prince-

ton Borders to do a reading. It was 11:40 P.M. when, exhausted and hungry and Devin having to go to the bathroom, we arrived at her door.

We found all the doors locked. “Well, I guess we’ll have to wake her up,” I said; we knocked, less and less gently, eventually rang both front and back bells. But she didn’t wake up. We tried again and again, calling “Mom! It’s us! Marion and Devin! Remember?, we were coming in tonight. You locked us out!” No answer.

The suburban neighborhood was quiet. I was getting concerned and considered calling the police, if I could find a phone. Dev and I prepared to camp out in the back yard. I convinced him to pee on the grass. It was summer but it felt a little chilly. I had a long-sleeve cardigan and I gave Dev my pajamas, for we’d noticed mosquitoes. Finally I decided to give it one more try, then wake up her tenants downstairs. By then it was 12:30.

The guy was very nice. He phoned her, she answered, and finally let us in. She had taken a sleeping pill, and had also forgotten. “I thought you said Friday,” she murmured, then giggled, a sort of telling giggle. She went back to sleep. Dev and I tried to raid the fridge, but there wasn’t much to raid. Dev wanted *warm* food. We couldn’t find cans of soup around. “There’s tuna fish salad,” she had murmured, absent-mindedly opening and closing the fridge, “and a couple of tomatoes.” I was worried and sad. Marielle had told me that Jeff’s brothers had simply said to her, “He’s going into a nursing home. It’s time,” and that she had gratefully shrugged and submitted. I hoped it wouldn’t be long, in particular not as long as it had taken to get Jeff into the nursing home.

But I had found another part time job. The math chair at Textiles and Science had been a colleague of Jeff’s and he’d wanted to find a “poet type” to teach calculus

courses. Another math professor there had also had Jeff as a teacher. “Omigod! Jeff Cohen!” he kept exclaiming. “And you’re his WIFE! Jeff was that really smart guy, and he was so nice, so down to earth. I remember, he was always talking about differential forms, saying how much easier they were to use than... than the other...”

“Tensors,” I put in.

“Yeah, tensors.”

We reminisced some more about Jeff, then I told him about his illness, Inglis House, and my book. “You must really be SOME PERSON,” he kept saying. Yes, I must.

One day when I arrived home from teaching, Devin told me, “Lurch called three times. And the last time he was really rude. He said, ‘Do you know what time Marion’s coming home,’ and I said ‘No” and he said “Can you take a guess?” and I said ‘No, I have no idea’ and then he said “I SAID take a GUESS.”

“Oh, no,” I sighed. “They’re cooking something up again. I’m not even gonna call them. I’ll call the floor and find out what’s going on -- after I check my messages and relax a little.” Well, four messages were from Lurch. And each of them consisted of his frantic, “Marion? Are you there?” [Pause} ‘Bye.” Another message was from Marielle. When I called her back, she told me that Lurch had called *her*. “Your father has a respiratory infection and the nurses won’t believe us. And they’ll only talk with a family member.” (The truth by then was that the nurses specifically wouldn’t talk with *Lurch*.)

When I called 2 Center I was told that the doctor had already been to see Jeff. Five minutes later the phone rang; it was Lurch. “Again?” I said. “I JUST talked to Jeff. I’m tired of this. Why are you calling? Is anything NEW happening?”

“I haven’t yet talked to YOU,” he said.

Thinking about it now, I should have said “Why SHOULD you talk to me?” But instead I said, “No, you haven’t, but you’ve left me four messages and you’ve spoken rudely to two of my children. Is there anything new that you’re reporting?”

Lurch paused, then said, “I don’t know what to say.”

“Then good-bye,” I said, and hung up. Then Arin, instead of complimenting me (as he sometimes did) on how I’d handled things, reacted by having second thoughts. “I feel sorry for Lurch. He is helping Dad. And hospitals really are terrible places...” I thought, what about feeling sorry for *me*?

But Inglis House was affirming to me. Soon afterwards I got a call from the social worker on Jeff’s floor. Lurch was banned from Inglis House. Moreover, I found out that some of the workers there had, independent of me, called him Lurch behind his back!

“If Dad got better,” said Devin, by now aged ten, “that would be bad for you, ‘cause it would take him time to learn how to move ‘cause it’s been so long since he’s moved, he’s forgotten, and Inglis House would send him home because he’d be able to move, but he *wouldn’t* move and you’d have to take care of him.” I’d had similar thoughts, and later kicked them around with Normie. “If he got better,” I began, “I still wouldn’t want him to come home. ‘Cause he wouldn’t REALLY be better. He’d be...”

“...just better enough to come home,” Normie finished, and we laughed heartily.

Eventually, Lurch was partially reinstated at Inglis House, being allowed to visit only

when the administrators were around, in case there was an incident. Even though I was pleased that they were concerned about Jeff's feelings and autonomy, I felt that was a bit too generous and I worried. And indeed, once Lurch was back in the picture, things got worse with Jeff. He refused to let his food run in overnight because, he said, he didn't trust the night staff. And he refused the Fleet enema, got impacted and dehydrated, had a bladder infection, and one day threw up, which was disastrous because if any of it were to get into his lungs he'd get very bad pneumonia.

I tried to reason with Jeff. "LET them take care of you. Don't complicate things and get in their way. Look, they're trying to take care of you. They know they can't cure you but they can make you comfortable. You're certainly not comfortable RIGHT NOW."

He nodded and said "hm", which sounded like an agreement—"hm", and he did then take a Fleet. But I doubted that would last. Such is the nature of that kind of dementia.

They had recently given Jeff a psych-eval and he had passed -- again, because a psych-eval isn't very pointed. To pass it, one need only know things like what year it is and how many fingers they're holding up. In other words, as far as I can fathom, a psych-eval isn't meaningful at all. It "evals" zilch. But they were talking about giving him something called a neuro-psych, stronger than the ordinary psych-eval. That didn't actually happen for a while, and then to no avail. It would have been a huge relief to me if such a test had shown incompetence. It would mean I could have control of his finances; I wouldn't have to worry about his pulling the stuff that he eventually pulled. Also, it might explain some things in our past. "Oh," I would feel, "So that's what it is. That's what it's been all along. So that's why nothing worked with him -- no matter how

much I explained, no matter how reasonable and eloquent I got, no matter how patient - and no matter how *impatient* -- and later, no matter how our therapist handled it. Nothing worked. That's why." In other words, a *good* psych-eval would have provided me some closure as well as relief from worry.

At any rate, Jeff did in fact get bad pneumonia. The doctor was talking about the possibility of a trach. It would be used only for suctioning; the rest of the time it would be closed and he could talk. Putting it in would, the doctor said, be "a piece of cake". It would improve Jeff's quality of life (as well as that of the Inglis House staff). He could get suctioned more easily, and better. Also, he could have the night ventilator attached to the trach, rather than on his face. No more sore nose, no more false alarms.

But for Jeff, it was one more step towards... well, as Marielle put it, it would be "the last thing, the very last thing". Also, Jeff was worried that, when he got back to Inglis House, they'd accidentally-on-purpose leave it closed, "to shut me up". I knew there was no convincing him that the staff had, at least so it seemed to me, amply demonstrated that his feelings were a high priority. Instead I said to him, "Balancing that worry against your gains, I do think your life would be better."

Marielle was upset about the trach and about the whole hospital visit. It wasn't the first occasion to be upset and it wouldn't be the last, but sometimes she seemed to be feeling as though it were both. I too was upset, but I also felt that strange detachment. To me it felt as though it had *happened already*. All of it. Feeding tube, pneumonia again, trach... it all felt like a play; I was play-acting, saying my lines and going through the motions in this never-ending drama, forced to stay on stage.

In November of '96 I asked the doctor whether he could give me at least some idea of the prognosis, in particular so I could know when it would be time to start visiting every day rather than twice a week. No, he said, it's probably not time to be up-ping the frequency of visits; twice a week was good. Something could happen suddenly, he said, but "sometimes people hang on for years". He added, though, "we're talking about years, not decades." I felt a slight jolt, but relief was my main reaction.

The Well Spouse Newsletter wanted me to keep writing articles for them, and I had plenty to say –including plenty that wasn't already in Dirty Details. The first article I wrote was "Sugar-Coaters and Other Non-Solutions". I said that sometimes the well spouse life is horrible and untenable, and that this calls, not for advice, not encouragement, not pep talk or sugar-coating, but introspection, acknowledgment, self-expression, maybe screaming and/or change. I wrote a few sentences describing my own well spouse situation, then launched into description of some of the less obvious sugar-coaters. I repeated what I'd said in Dirty Details about the word "stress", how for well spouses that word is a sugar-coater. Instead of "stress", I preferred the term "dire straits". And instead of "hardships", I coined the term, "impossible-ships". I also bemoaned the over-emphas-is on "humor" and "happiness". Well spouse meetings were full of in-joking and laughter. So was my own household. But humor is not the solution. As I said in Dirty Details, "a sense of humor is not a sense of happiness."

Throughout my dire-straits years I had been very happy. I possessed "inner happiness", as they say, and I also possessed "outer happiness" brought on by my sense of

fun and joy, and love for my work and family, including the relatively recent birth of Devin. Yes, one can be happy and in dire straits at the same time. But happiness, again, is not the solution. Nor is being made to feel guilty if we're not happy.

I analyzed the “marriage vows” sugar-coater. Similarly, the “responsibility” argument, both designed, so it seems, to keep well spouses and other oppressed people in their places. At the altar I'd thought that “in sickness and in health ‘til death do us part” meant *stay* with him. I didn't know it meant take care of him. I certainly didn't know it meant nights, lifting, and toilet. Few young couples know what “in sickness” can entail. And about “responsibility”, there were other people besides Jeff who needed me, whose lives intertwined meaningfully with mine, and to whom I had made vows -- my children, my sister, my aunt Faygie, friends, students, colleagues -- and my self. In my article I argued that to plunge into “responsibilities” towards the care recipient and to neglect responsibilities towards the rest of the world seemed... well, irresponsible.

I analyzed the often-heard dictum: “It's not him I'm angry at; it's the disease.” Suppose it *was* him? Would we then have less permission to be angry? Somehow it seemed harder for society to accept anger towards a person than towards a disease. But anger towards the care recipient is often justified. Indeed, no one is perfect; why should a care recipient be? Whatever faults she or he had before the illness must have carried over into the illness, possibly magnified. Previously reasonable fearfulness, demanding-ness, self-centered-ness, even abusive-ness, get worse with chronic illness. Also, any need for emotional care giving can turn into a need for physical care giving.

I also cautioned against too much of the type of praise for care givers that takes the form of the flattery that gets you nowhere. "You're doing a wonderful job, KEEP IT UP." No thanks! Imagine telling a slave, "You're soooo good at picking cotton. We're going to increase your hours." That did, and does, seem to me the spirit in which praise is often given care givers. Support groups say, "Don't worry; we know you're doing your job well. You've made the RIGHT CHOICE." Well, just because we made that choice when our spouses' illnesses were first diagnosed, doesn't mean we should *continue* to make that choice. The decision to be a care giver is one that should be up for renewal. In fact, in an ideal world, social workers would help us re-evaluate. Besides, how can we possibly know whether or not a particular care giver is "doing a great job", when we haven't gone into her home -- specifically, her bathroom -- to observe her.

The other side of the coin, of course, is criticism of caregivers. What do people criticize a care giver for? Almost never for not "doing a great job". Complaining is what people criticize care givers for. If they complain, many people call them "selfish". My own word is "self-ish" -- possessing a self, being aware of and attending to that self, and to how it can benefit other people's selves -- and not only the care receiver's.

The history of complaining is extensive and impressive. Slaves have complained, blacks have complained, women, etc. It started out as individual griping and wound up making change. If members of an oppressed class didn't complain, the class would be in big trouble forever. Most movements and revolutions start with complaining. Even if it's only individuals complaining for only themselves, still, such complaining propogates.

Centuries ago John Stuart Mill said “Dissent is the prelude to revolution”. I would add “And complaining is the prelude to dissent”. And sugar-coating isn’t.

I ended that article by stating my impression that sometimes the very word “caregiving” is a sugar-coating. It is, after all, composed of two rather sentimental words, words which society seems to feel comfortable with and unthreatened by. Like “loved one”, “care giving” seems so harmless. In the article I quoted the beginning of my poem, “Caregiving: The Word”. “I hate it. / It implies we give. / Like calling being mugged purse-giving. / Like calling being raped sex-giving. / Like calling being murdered life-giving.”

If well used and well directed, I wrote, sugar-coating can be beneficial. It can help us get through things, feel better, move more gently through the five stages towards acceptance. It can even help us cry, as we realize the wishful thinking we’re indulging in. Yes, sugar-coating has its rightful place in the grieving process. But too often it’s not well-placed, but perceived and treated as the *final* stage in the process, instead of acceptance. Sugar-coating alone doesn’t lead to acceptance.

The annual Well Spouse weekends began to include Saturday night dances. The choice as to what to do about them was left to the individuals. Many of us didn’t go, many went and just watched, many danced in groups, many in couples just for fun, and some danced as serious couples. I was always very moved by these dances. To me the dancing said, “We’re still citizens, still human. We have the right to dance.”

I knew some of the serious couples. They were committed to their marriages and to the care giving, yet also in tune to their own needs. I knew that when Mary went home the next day, she'd spend the rest of it trying to convince her husband that he wasn't in pain. It moved me almost to tears to see her now, dancing with Ken, throwing out her arms, and back her head, smiling and laughing.

Most years I had been one of the watchers. But in October of '96 I couldn't help myself; they were playing Light My Fire and I just had to get on the floor. I danced by myself, or with a female partner, on and off, from 9:00 to 11:00. I threw out my arms, and back my head, smiling and laughing like Mary. I didn't know what I would do if a guy asked me to dance, especially if it were a slow dance. There was no guy there who attracted me. I did, however, look around.

At dinner that year all the well spouse authors were presented with awards. There were three of us. Maggie, founder of Well Spouse Association and author of "Mainstay", talked at length about each of us, reading two quotes from each book. We were presented with green ribbons decorated with gold coins which, I later realized, were wrappings for pieces of chocolate. I have always fantasized a "testimonial dinner" in my honor. This was not a testimonial dinner, but it was a testimonial dessert!

The Star Ledger sported the kinds of things the TUP editor had warned me about. "Along with honesty and directness, the book has an ugly and bitter ring. At times, Cohen comes off terribly ego-centric. She admits that part of her reason for writing is to expiate the guilt over her burn-out and remember the untenable circumstances exactly

why Jeff is in Inglis House in case she ever has a change of heart about letting him come home.” I bristled. That passage was completely misinterpreted. It was meant to be bitter, to say, tongue in cheek, that one reason for writing was to make it very clear how bad it is/was, so we don’t forget and wind up concluding “It wasn’t that bad” and doing it again. And where did “guilt over her burn-out” come from? Perhaps the reviewer’s own agenda? How, anyway, would any of that be “ego-centric”? If the oppression I’d been trying to escape had been an abusive relationship or a molesting parent, I would not have been dubbed “terribly ego-centric”. Authors of books about escaping those more recognized forms of abuse don’t get called “ego-centric”.

But a far worse media experience was yet to come. I’d been excited about being on Channel 6 -- AM-LIVE, even though a few people warned me about Wally Kennedy. “He asks dumb questions,” said my friend Cathy. But publicity is publicity.

Wally Kennedy tried to make it into a battle between Normie/me and this other couple. They showed the couple at home; she was in a wheelchair but had plenty of use of both hands and clearly didn’t need care giving. “I’ll NEVER put her in a nursing home,” her husband vowed. I was introduced as “Marion Cohen, author of Dirty Details and a woman who decided that she’d had enough of taking care of her spouse and decided to institutionalize him and walk away from the marriage -- Oh, I see she’s shaking her head, rather vigorously. What? Did I say it wrong? What IS the story. Tell us...”

The whole thing was insulting but I told them what the story was, including how, eleven or so years ago, I was pretty much like the husband of the couple we were now pitted against, back when Jeff was in much the same condition that this wife was in now.

(Except, I didn't vow that I'd "never put him in a nursing home".) This publicity wasn't easy. For each question I knew I had only a few seconds and I kept thinking, "Omigod, which of the many things that I have to say should I choose?" I didn't get to talk about the "conspiracy of silence" or Jeff's complete paralysis or the feeding tube. I did, though, get to say "dire straits" and "nights, lifting, and toilet". I also got to talk about the last chapter of the book, the process of making "the nursing home decision", how one step in that process had been: "Seven years' dire straits, okay. But not a LIFETIME."

When I got back, family and friends all told me, "You and Normie were great. Wally Kennedy was a jerk." I wasn't quite sure, though, whether people seeing me for the first time on that show could tell what my book was about. So it felt great to hear my phone message: "I'd like to get a copy of your book. Borders is out of it and Temple University Press will take a couple of weeks and that's not soon enough. I'm wondering whether I can possibly buy a copy from you". And that evening, at a reading I was doing, people told me they were there because they'd heard it announced on AM-LIVE. One of them hugged me. And next Calculus class when I asked my students, "Well, who won, me or Wally Kennedy?", one student called out, "You! I'm gonna write the station."

I was seasoned enough to know the limitations of publicity. But one night I dreamt that the police were after me for "walking away from the marriage", as Wally Kennedy had said and, as the Star Ledger articles had said, visiting him "only" twice a week.

In November of '96 Lurch harassed my kids some more. A typical episode was the one Bret told me about the morning afterwards. At 3:00 A.M. Lurch had phoned Bret.

“Could you please call the nursing station and ask them to move your father’s leg.” We guessed that the nursing staff had refused to listen to Lurch’s 3:00 A.M. phone call.

“It’s very rude of you to call at 3:00 in the morning,” Bret had said to Lurch.

“Come on, be a good son,” Lurch had answered.

“Forget it, I’m going back to bed,” said Bret, and Lurch had then said, “WHOSE bed are you going back to?”

Indeed, Jeff must have talked to Lurch about one of his other issues; to me he had sometimes gone on and on about how he supported us financially. It was understandable that he wanted to keep reminding and reassuring himself of that. I felt his pain and unbearable frustration. But the kids and I had done more than our share of *non*-financial support. And I was not about to bear the brunt of Jeff’s issues, and neither was Bret. I wanted to tell Lurch that Bret had, at the age of twelve, “done nights” with Dad. He’d managed the ventilator, handed him jars, and so on. But I was not about to specifically contact Lurch in order to tell him that, or anything else.

I planned to do my darnedest to protect my kids from Lurch’s harassment. I had already spoken with the acting head nurse on the floor and she had suggested I write to the doctor, which I had done. I was prepared to have Bret’s phone number changed, as well as my own -- just as, three years before, I had planned to run away from home, with my kids, if they sent Jeff back.

My well spouse friend Tanya’s husband was in the Day Program at Inglis House. He was a Ph.D. scientist too, and he visited Jeff once a week. One day I got a phone call

from him. “This is a friend of Jeff’s at Inglis House; Jeff asked me to give you a message. The message is, he hates it at Inglis House and he wants you to know that.”

It was 6:00 P.M. I had just woken up from a nap. I was between the “Celebrate Age” EXPO at the Philadelphia Convention Center, where I’d been given my own booth to sell books, and the organizational meeting of the Center City Care Givers’ Support Group. I could have said just “Okay, thanks for the message”, but I wound up saying, “I know Jeff’s unhappy and I’m ALREADY doing everything I can to make him happier. There’s nothing else I can do. And Jeff knows that and you should know that, and it’s very intrusive of you to be calling me.”

“Okay,” he said. “I’m sorry.”

“Okay,” I said, and hung up. The next day Tanya phoned me. “Marion, I’m so sorry about that phone call from Bill.” He had told her he was planning to make the call and she had tried to talk him out of it. She had said the things I had said to him, ending with “What exactly is it that you think Marion can do?’ Mostly she and I giggled, as we talked about “our men” and the stuff they “cooked up”. Yes, we talked “girl talk”, pretending we were regular girls, with regular men.

In general Tanya is a pretty sharp lady, and sometimes that was good for me and my books. At the Well Spouse Weekend, for example, one woman took up more time than we would have liked telling us about this special device designed to help one lug and maneuver around one’s unwell spouse. She passed out pamphlets. “It’s not a scooter,” she cooed. “It’s not a Hoyer lift...” It looked like a giant praying mantis, and I was grateful that it would never grace the floor of my living room.

“Well, I could tell the nursing home about it,” some people murmured politely, and I couldn’t help blurting out, “I know it does lifting, but does it do nights and toilet?!” Then Tanya took the floor. “You know,” she said. “I don’t know whether I WANT to know about a special device that will enable me to take care of my ill spouse for the rest of my life.”

“Right on!” I called out.

“Well,” said Tanya, “I couldn’t have said that without reading Marion’s book. It’s her book that brought me to the point where I could think and say that.”

“What’s the name of her book?” someone asked, and from all sides came “Dirty Details!”

A month later one of the *cats* needed care giving. Mirage had been biting his tail. It was bleeding. The vet said he had fleas and would need to have antibiotics and flea medicine on his tail. The other cats also had to, because fleas are catching. Mirage also had to wear what they call an Elizabethan collar, this thing that looked to me like an old Victrola; it surrounded his head so he couldn’t bite his tail. We couldn’t quite figure out how to put it on him, and once we did, it came off in no time. The whole thing freaked all of us out. “He won’t be able to clean himself,” Bret said. I wondered whether it might be dangerous; how would he even see? Mirage was walking backwards, then forward again. I worried that Bret might be criticizing the vet and I’d have to find another vet. The whole thing smacked of Jeff-stuff. What was I supposed to do about everything?

“Bret,” I suddenly said, “look, I don’t know what else to do. You wanna do something else, find out about something else. I’m not gonna spend my life searching for some al-

ternative cure for CATS, any more than I'm gonna spend my life looking for a cure for M.S. I feel as though everyone's trying to get me to devote my life to..."

"Ma, I'm AGREEING with you," Bret interrupted. "You're TIRED, Mom." And he went up the stairs. Apparently HE was tired, too. Devin and I were now alone in the kitchen. "I feel as though my family's trying to... or not supporting me... or..." I began.

"Your family?" Devin said. "Your WHOLE family? Am I doing it, too? When you say that, I feel as though..." And so it went.

Next morning, though, things were much better. I apologized for implicating them in things, and Bret said seriously, "I think I know how you felt. I got an idea from some of the things you said in Dirty Details."

One day I arrived at Jeff's room to find, not only Lurch, but Lurch's friend Joel. Many years ago, Jeff had met Lurch through Joel. Joel was a converted Jew with both a doctorate in physics and a M.D. degree, both unused; he lived at and was supported by Hillel. The two of them were wandering around Jeff's room. Then Joel stopped by the window and began davening. I figured they might need privacy and I also didn't want to be in that room with them. So I excused myself, told Jeff I'd be back once they'd left.

I went to sit and do math in the lounge. But after fifteen minutes Joel came in. He began giving me medical advice. "I think the leorazol [spasm medicine] might be making Jeff drowsy and clouding his thinking. Also, it might be causing increased salivation."

"Joel," I said, "he spits because he's afraid to swallow. And he's afraid to swallow because his disease has progressed to the point that..."

"That may be," interrupted Joel, "but..."

I didn't let him finish. "Joel," I began again, "the way I see it, and the way it's been explained to me, the crucial thing here is the bedsore. Yes, there are all kinds of side effects to everything but the IMMEDIATE thing, and the thing that I, for one, am concerned about, is the bedsore. The spasms are very probably aggravating the bedsore. And I do hope that you encourage him to have the nerve block, the Bow Tex..."

"Oh, I can't in good conscience do that," Joel replied. "I don't feel that's the way to go..." Joel kept talking. Something about getting a third medical opinion. From yet another doctor. More delays. "It's not clear." "We have to check it out." And then, rather suddenly, "Yes I know YOU want the nerve block but you can't run Jeff's life for him."

That did it! "I'm not trying to run Jeff's life. But I think that you two are. And if Jeff wants you to, that's fine with me. But I want you -- both of you -- out of MY life." I had been gathering up my books and papers and was now walking out the door. I heard Joel behind me murmur, "What? Huh?"

"Stop interfering in my life," I repeated, walking as fast as I could. Before going into Jeff's room I stopped in at the head nurse's office to report what had happened. When I went to Jeff's room, I told him too, adding that I was pretty upset. "Joel wasn't supposed to say anything to you," Jeff said. "He was supposed to just go get you."

"It's not only a matter of what he SAYS to me," I answered. "It's what he's DOING. That bedsore is raging away." At the time I was willing for this nonsense to be the death of him, but not the death of *me*. I didn't want it to be any *morbidity* of me either.

At the faculty party at Philadelphia University there was dancing. I didn't have the nerve. Especially the macarena. But it looked like so much fun. I wished I had the nerve.

The next day, doing lecture preparation for a new part time position at Drexel, I thought, "Fourier series is as good as the macarena." Still, for Chanukah, when Marielle and Matt asked me for gift suggestions, I suggested a tape of the macarena. I planned to practice dancing alone, perhaps in preparation for dancing not alone.

On Christmas day 1996 I decided to read over my adolescent diary. And when I did, I thought Man! was I hot! I certainly didn't hesitate to go after what, meaning who, I wanted! When I'd seen that Jeff, the "boy from the bus", was at that Y dance and when he started dancing with and paying attention to me, I excused myself and called home. "Mommy," I said, "Daddy doesn't have to pick me up this time." My mother told me that "Daddy" had already left, but when he arrived I sent him back home -- on the mere chance that Jeff would wind up offering me a ride, which he did. Reading that part of my diary I said aloud, "Good for you!" Then, still aloud, "could I do all that again?"

Relli, a writer friend, had been diagnosed with M.S. She tended toward depression and had been increasingly fragile. And I was increasingly wary, careful not to become her best friend. I did not want to be saddled with any more caregiving. She did have a son, to take care of anything that might need to be taken care of. Still, I was wary.

But our mutual friend Nancy didn't feel the way I did. One morning she phoned me, sounding terrible. "Marion, can you help me?" she asked.

I was wary of that kind of thing, too. "What do you need help WITH?" I asked.

"It's Relli. She's suicidal. I can't get ahold of her brother or her doctor and... my kids are coming home and... can you go over there and stay with her?"

“Uh, Nancy...” I said. “I can’t get involved in that way. I’m already up to my neck with Jeff, and the last visit was especially hard. I can’t be Relli’s care giver or next of kin...”

A little later there was a phone message from Nancy. “Marion, Relli is dangerously depressed; I’ve been over there every day making her breakfast and staying with her... Marion, on your birthday, January 2nd, can you go over there and make her breakfast.” Listening to that message made me absolutely furious. But since it was a phone message and not a conversation I had the pleasure of shouting out “No way!”

A little later I phoned Nancy. She told me that she was in touch with Relli’s psychiatrist, who wanted to put her in the hospital. Nancy finally blurted out “It’s not fair to ME if Relli doesn’t go into the hospital.”

“That’s right,” I answered. “It isn’t.”

Later still she phoned me back. “Marion, I’m SO afraid Relli’s not gonna let them put her in the hospital. I’m really afraid they’re gonna put her in a taxi and send her home.”

“You sound like I felt when Jeff was in the hospital and I’d said I wasn’t taking him home. I was so afraid they were just gonna send him home anyway.”

“And?” Nancy asked.

“And I told them there was no one at home to take care of him. And Relli doesn’t LIVE with anybody. THERE’S NO ONE AT HOME TO TAKE CARE OF RELLI.”

So then Nancy and I were able to communicate using that metaphor. “Will you tell Relli that?” she asked.

“I sure will,” I answered.

“And also, tell her that... tell her to go into the hospital...”

“Yup.” “Marion, really lay it on her thick.” “I will.”

And I did and it worked. But I felt manipulated. Nancy was taking on stuff and assuming I would be the same, trying to draw me in. It wasn't up to her, what or how much I did for Relli. If she decided to do too much, that wasn't on me. And right now what occurs to me is: Nancy got a very small taste of caregiving. And it drove her to panic.

At my Lancaster Borders reading in January of '97 a “counter-revolutionary” broke in. “My husband died a few months ago and I would give anything to have all that back... It made me stronger. It depends what you DO with it. We can be POSITIVE about it”.

“The lady doth protest too much,” I thought. But I let her talk awhile, then I tried to deal with what she'd said. She soon “had” to leave early and then people started really talking. And judging from the number of people who came up with books for me to sign, it was clear how they felt. If they had formed a line, that would have been the line that I'd missed at my Philadelphia Borders reading.

In March of '97, through our mailbox, arrived a handwritten letter addressed to Jeff: “To whom it may concern: You know that you raped me. You jerk. That is why you better send me a check for \$500 as agreed. Otherwise I will go to the police. You know the police will believe me. They always do. Or perhaps the next letter you receive will blow up in your face. Death to men. Give me my money. Send cash only and send it to me in an envelope with no return address. You probably forgot my name when you raped me.” There was both a name and an address, and then, “You have one week before I call the police. You jerk.”

Of course Jeff wouldn't, and couldn't, rape anybody. But that letter still felt scary.

CHAPTER VI: A NEW ERA

At the end of the Drexel quarter the assistant head asked me, with perhaps a slight smirk, “Do you want to stay an adjunct?”

I perked up big-time. “Are there any other options?”

Indeed there were. Drexel had three full time non-tenure-track positions opening up. And they wanted me to apply. Full time! I’d thought that was impossible. I’d thought I’d have to forgo fulltime, as the price for being bigtime mother, writer, career-ly immature person. Full time would be, I’d thought, one of my life dreams that didn’t make it.

The load would be 12 hours, but three courses, not four. That meant only three “preparations”, three sets of papers to grade, three Finals, and so on. I sent in my application the next day. I also told Textiles that I would probably not be able to teach there the following fall because of my almost-firm full time offer from Drexel. Textiles responded by giving me a most gratifying “exit interview”. The dean said he was really sorry to lose me. “Harry [who’d observed my teaching] had nothing but good things to say about you. We can’t offer you what Drexel can offer you. But one thing we do often do: If professors from other places come in and teach a course we can pay them comparably. I’m thinking maybe we could use you in other areas, too, besides math. You know, your writing and your poetry...”

It all seemed strangely non-Kafkaesque. I had done a good job and was being treated accordingly. That had not happened before, not to that extent. I wondered whether it was true. I didn’t have an actual hiring letter and wouldn’t until the applica-

tions were officially processed. “And Drexel definitely has courses for you?” Jeff asked. “They won’t suddenly not have anything and then you won’t have Textiles, either?” Indeed, Jeff’s life had also been full of Kafkaesque happenings.

On the evening of April 30, ‘97, Marielle called to tell me, “I’m in labor.”

She’d been at it awhile. The night before she hadn’t slept well and they’d been in the hospital all day. But Marielle sounded great. Not scared or tired. But I had a bad cold and was mourning in advance the loss, not being able to rush to the hospital as soon as word was given. I tried hard to get better, spent the next day in bed with vitamin C, took a hot bath with Tiger Balm. I lay there and thought about Marielle. “Well, I guess she didn’t deliver by morning.” “Well, I guess not by early afternoon.” “I hope she got some sleep.” By 4:00 I was starting to worry, about the pain she might be in and about little Jack. But around a quarter to 6:00 we got the phone call. “Mom?”

“Elle! How are you? What’s happened?!?”

“Well...” her voice sounded bright, “we have Jack!”

“Oh, Elle,” I exclaimed. “I love you!”

Jack had already nursed -- “well,” Marielle emphasized. Now the three of them were on the bed -- Marielle, Matt, and Jack. Six pounds, 10 ounces, a dimple -- and I couldn’t go see him! Congested and coughing. I spent the next day in bed, watching jealously as Arin and Dev went out the door to go see Jack. The next morning Marielle called to say, “Mom, the nurse said you could have come all along...” I rushed through breakfast, ran out, bought film, took a cab. And you know the movie “I’m All Right, Jack”? Well, Jack

was more than all right! In a few weeks I noticed another dimple. Jeff, of course, had not yet seen any dimples, nor anything else of his first grandson.

I was still worrying that something would go wrong with the Drexel job offer. For a while the focus of this worry was getting the chairperson at Temple, where I'd taught a few years before, to write me a recommendation letter. All the others were in. I had to keep reminding him. Eventually he did write the letter and phoned me to tell me, adding that it contained "nothing but good". All that remained was to wait.

Lots of people besides Jeff needed me, and that felt gratifying. One friend needed me to listen to her bitch about her ex. Another lost a grown son and needed me, because she knows I'm experienced "in these matters". Home-schoolers needed me to tell them what to do and what not to do. Readers and audiences of Dirty Details needed me. Lots of people needed and, I assumed, appreciated me. But only Drexel would, if I got that job, pay me well. I wanted someone to need me enough to pay me well.

That was the wrong time in my life for one of Jeff's doctors at Inglis House to address me, repeatedly and insistently, as *Mrs. Cohen*. "DR. Cohen," I corrected him.

"Well, you're also MRS. Cohen," he said.

As nicely as I could, I answered, "I'd rather be called DR. Cohen," and then, "You know, YOU're also MR. R." Why was it so important to him that I be MRS. Cohen? It bothered me. I wondered whether Hillary minded being called Mrs. Clinton?

Instead of "Mar, toilet", it was now "Mar, napkin" -- meaning put a napkin in his mouth to try to soak up what the suction tube hadn't, or "Mar, nose" -- meaning he needed to blow his nose. I was a whole new brand of tired. Tired of his determination to go on liv-

ing, that matter-of-fact-ness, that stoicism which some people felt was “amazing”. His Advance Directive specified all heroics. He would live through pain, coma, mindlessness. He believed life always meant hope; a cure for M.S. would be discovered. I was tired of my life being decided by somebody else’s beliefs.

And I was tired of that pole in the middle of his room. It’s okay to be reminded of one’s own mortality, but two full afternoons a week was not my choice. I wanted more choice regarding the extent to which I was reminded of my own mortality..

On July 5 1997 we returned from our beach vacation to a week’s, and a kitchen tabletop’s, worth of mail. I had been dreading that moment. I thrashed through it and, noticing nothing from Drexel, breathed a few sighs of relief. And then suddenly, out of nowhere, fell a business-sized envelope. And yes, it was from Drexel. “We have filled the tenure-track position...”

I phoned my friend Cathy. “I don’t exactly hate myself but I’m not proud of myself. And my kids won’t be proud of me. Is my turn ever gonna come? What went wrong? Did students somehow complain about my course? Did the Temple guy write a bad letter?”

It felt good to have somebody to agonize with. Together we wondered what would happen when, on Monday, I phoned the assistant head to try to get some information. “And Marion,” said Cathy. “I don’t NEED you to get that job, or any job. I know you’re wonderful and I love you.” Then we hung up and went to meet each other for dinner.

On my way out I took another glance at the letter. Oh, it was the *tenure-track* position I’d been rejected for. Maybe they hadn’t yet sent out the letters about the non-

tenure-track position, the one for which I'd been asked to apply. So there was still hope. I could enjoy my dinner with Cathy.

And indeed on Monday I was told, "Yes, you're definitely being considered for the teaching position. In fact, we want to be able to offer it to you. It depends on the budget..." When I told Cathy she said, "They want YOU. That's pretty cool." Although I had lost good jobs before because of budget problems (and would again), that phone call from Drexel made a big difference in my self image. I no longer thought about down-trodden, no longer felt that the only things I got were non-money-making things.

But weeks later I was still waiting. When I finally phoned Drexel I was told that it would be about two weeks before they knew about the budget. She ended with "It'll be good news, I'm sure." But when you're a bereaved mother of a newborn baby, and when you're a well spouse, and when you're both, nothing is ever sure.

The two weeks came and went. I realized how seriously I wanted this job, how fervently I wanted to be doing math in my old age. I had done plenty of math in my *young* age. Math had been my be-all and end-all; I was always working on "some math problem". Now I wanted to go back to my beginnings. I wanted to do what Jeff and the kids had interrupted. What, indeed, I had wanted them to interrupt. I wanted to do what I knew there would soon be no one to interrupt. And I wanted to be able to say to that thing -- that math -- I wanted to be able to say, "Alone at last."

I also wanted money for re-doing the house. I was tired of antique. I wanted modern, what they call "minimal". I loved shopping, so I described what I wanted as "minimal but not finite!" I had gotten, at flea markets and in the Salvation Army, a cool red 50's table,

six designer chairs for \$20, and four black and chrome chairs for \$28. But furniture wasn't all. There were, in the bedroom, too many of those otherwise-fabulous pilasters. I wanted to get rid of the ones in the corners, keep only the ones bordering the windows and doorway. Also, the ceiling was in terrible shape, too many moldings. All these gigantic things needed to be gotten rid of. Plus, the house needed painting. I knew I couldn't get *those* things in the Salvation Army. Those things needed money. Real money. Full time-job money. Meaning full time job.

On September 8 I decided to call Drexel again. I had done some processing. I'd decided that, in my fifty-four-and-a-half years, bad times had come and gone. In particular, they had gone. And they'd done nothing to take away either my happiness or, as I sometimes called it, "the me in me". Not getting this particular job would be no exception. Sure, being a full time math prof had been a life dream. But it had not been my only life-dream. I didn't have to realize *all* my life dreams. No, I didn't have to live in fear of what the verdict would be. I could hope they made the right decision, even feel nervous, but I didn't have to live in fear. Living in fear was when Jeff fell to the floor while my ankle was broken, nobody else in the house. There was no reason to live in fear now. As I dialed Drexel I had butterflies and heart-thumping but I also thought "Look, you've had butterflies and heart-thumping plenty of times before."

And the news was good! I did get the job. "DID, DID, DID," I wrote in my diary.

I was thrilled to be getting my own office. It wasn't big but it wasn't small either. I loved it, more than the tenured professors', because it had a large window that overlooked beautiful trees. Also, the assistant head promised me that, during the next quar-

ter, she'd assign me Abstract Algebra, my dream-course. For now, the teaching felt great. Knowing that I'd been given me a full time job made me feel completely confident. After my first class I spent a couple of hours in my office, making phone calls to friends ("Guess where I'm calling from?!"), planning for my next class, working on the associative arithmetics problem, and just sitting. It felt so romantic, doing math full time again, in an official way, after so many decades. After my next class, a few colleagues poked their heads in to introduce themselves. I especially enjoyed Charlie, who asked, "Are you the same Marion Cohen who was working here part-time back in the 70's?" He seemed excited, showed me the '76 teaching assignment schedule with my name on it. "Oh, an antique!" I quipped. Our conversation was interrupted by a student of mine who had questions, then a student of Charlie's had tracked him to my office. It was all so much fun. I decorated my office 50's style. Every once in a while I'd get the feeling that something would go wrong. But then I'd remember, "It's not LIKE that any more."

Part of the joy was telling others, and plenty of people were happy for me. "Marion," said Freda, "NOBODY gets a full time academic job after the age of 50. They must be really impressed with you." "This is really something to celebrate", said my sister, and she arranged for her, Marielle, and Matt to toast me at 4:00 that afternoon.

But very often, when I told somebody about the job, that person would respond by asking "How's JEFF?" or "How's JACK?" It was almost funny but it also felt hurtful. One day three people did that whom I would have thought wouldn't. A woman from Rittenhouse Square admired me for my encouragement in thrift-shopping and prolonged nurs-

ing of babies. Now, though, when I excitedly told her, first thing, about the job, her immediate answer was “And how’s JEFF?” I’m not imagining or exaggerating this.

I was prepared to the quick. “Hey, I’m not READY to talk about Jeff yet. Jeff’s... you know.. the same. But I... well, I’M different!” With Jeremy, it was a different story. Instead of “How’s Jeff?”, he suddenly smiled, turned to DEVIN, and came on with “Hey, I bet DEVIN’S the one who helped you get it. Yeah, it’s all because of DEVIN. DEVIN gets the credit.” Very quietly and centered-ly I answered, “I want the credit for this one.”

Yes, it seemed there were people who, for whatever reasons, needed me to not have that job. But I did have that job. It was the beginning of a new era. Unfortunately, it was the beginning of a new era in other respects as well.

CHAPTER VII: NEW ERA IN A BAD WAY

So there I was, reclaiming my life and then-some. I had a book, the possibility of another book, and a new full time job. The downtrodden days were over. I was a citizen.

The kids were doing great. Devin had learned reading and writing via dictating his stories to me, and Bret had taught himself to crochet; he was making and selling hats. That and drumming were his passions. He seemed happy for an 18-year-old, and he talked about how happy he was -- as he crocheted, as he drummed, as he cooked.

With Jeff I was being a little more vocal concerning his situation. "I know you say you want to live as long as possible, and that's what everyone here at Inglis House is honoring, big-time, but I think you should also think about what that means for me, and the kids. I don't want to say anything hurtful, but I think you should spend some time and energy and imagination on that."

Jeff nodded. "I'm glad you're telling me these things. I've been wondering what you've been thinking." But every stride that he made towards being a Mensch was, ultimately, over-shadowed by the progression of his illness, along with its dementia.

And soon there was another person to worry about. One day Bret told me, out of the blue, about a revelation he'd had. "Nothing can stop me," he said. "I'm going to change the world." He paused. "You'll see." I simply shrugged, thinking "huh?"

A little later that day he said, "I'm ready to teach you and I'm ready to learn from you." That sounded a little scary, but I smirked, "In order to learn from me, you have to LISTEN at least a little bit." "Yeah, I know," he answered. "I'm getting better at that."

I asked him whether he was high on anything. “Funny,” he answered, “a bunch of other people asked me the same thing.” But no, he said he wasn’t. A few days later, in the kitchen, he was all hepped up, rushing as usual to go out but also anxious to talk. “I’m making my debut,” he told me.”

“Oh, you’re reading your writings at Last Drop Cafe?”

He nodded. “Good luck,” I said. Then I glanced at the foot-and-a-half-high pile of records that, at least two days before, he’d left on the corner of the kitchen table. Not to mention a couple of balls of yarn, plus other assorted items. “Uh... Bret...” I said, in my mother-lingo. “Could you... uh... take a minute to bring those records upstairs?”

“I’ll do it later, Mom, I promise.”

“Uh... I think you should do it now.”

And then he got upset. Really upset. Angry. Ugly. “I’m very busy,” he began. “I don’t have time for this kind of thing.” Then he fumed some more. “Mess is beautiful,” he said, “and the world doesn’t realize that. I’m going to teach you. I’ll show you the way.” As he spoke, though, he was cleaning the table, almost all of it. Eventually he said, “SAY something.”

But I didn’t. I shrugged only once, and then was quiet. Finally I said, “I have nothing to say,” and then, just before he left, “thanks for cleaning up.”

“It looked better before,” he said. “I’ll explain it to you later.”

After he left I phoned first Marielle and then Cathy. “Well,” said Marielle, “I guess Bret’s going through yet another stage.” Cathy’s reaction was “Well, sounds like an 18-

year-old.” But I had felt scared and abused. And we all felt that Bret seemed delusional. Then Devin came in. “Are you all right?” he asked me. “I heard Bret screaming and you being quiet. I thought maybe Bret beat you up.”

The next morning Bret talked to me about publishing my “math poems”. “How much do you want me to pay you? he asked. The crowd at Last Drop had loved his stuff. “You’re something really special, Bret,” they had told him, or so he said.

“Bret,” I began, “I have to tell you that I -- and Dev, too, by the way -- felt scared by the way you were acting last night. It also felt abusive.”

“Yeah, I can SEE that,” Bret answered.

“Right,” I nodded. “In fact Dev ran downstairs because he felt scared and when he came back up he asked me whether I was all right; he said he was worried you might have been beating me up ‘cause he just heard you yelling and me not saying anything.”

Bret thought about that and when I asked him, “were YOU scared?”, he answered, “Yeah. I was VERY scared. And I felt really threatened ‘cause it felt like you were saying you didn’t want my things around your house.” As he spoke he got teary, more and more. Eventually I said, “Bret, are you crying?” He nodded.

“I guess it really matters to you, that I accept your things.” He nodded. “Listen, as you know, I like and accept your things, even if they’re not my things, even if they’re not my taste. I just don’t want two feet of records on the kitchen table for days at a time...’

He seemed to understand and continued to look teary. “Come here, Bret,” I said. He did and we hugged. “No, I mean SIT DOWN. I’ll HOLD you. Not just a hug but a hold.” But Bret said, ‘I’d rather sit in this chair.’ We were in his bedroom at the time and “this

chair” was hanging from his ceiling. “From a main beam,” he assured us. Later he asked, “Can you teach me some geometry?” then “Terry and I wanna sit in on your classes sometime.” He also talked about his plans to build a house on the Wissahicken. “Do you want me to build YOU a house on the Wissahicken, too?” he asked. Then he said he had lots of ideas how to cure his dad (who’d once gone on and on about building a house on the Wissahicken).

A couple of nights later I lay awake at 1:00 A.M., having just finished doing math. My eyes were closed. I was just about to sleep. Then I heard Bret on the steps. Then I heard him gingerly open my door. Then I heard him linger. He really needed me. But I kept very still. A few minutes later I was continuing to keep still. But something made me look around. I saw Bret lying on the floor next to my bed, wrapped up in one of his blankets. “Whatsamatter, Bret?” I asked.

“I needed more light.” he said.

“Huh?”

“I was really scared.”

So I listened. Asked questions. He was really scared. “Of what?” I asked.

“Of everything,” he answered.

“Existential-scared?” I asked. “Like we were talking about the other day?”

“Yeah.” He talked about colors. Too much about colors. And confusion leading to understanding. “Bret, are you withdrawing from something?” I asked again.

“Yes -- a six-day fast. That’s the longest fast anyone ever did the first time.”

“So why’d you do it?”

“I didn’t realize it was six days; I thought it was only two days.”

“So THAT explains it,” I said. “And did you have anything to eat NOW?”

“Yeah, I had an orange and some water.”

”Maybe you should have a little protein.”

“I HAVE protein. See?” He showed me his blanket. “White. That’s like protein.”

“It’s LIKE protein but it’s NOT protein.” He got up, went down to the kitchen, and came back with soy milk, a tomato, and other food. “Bret, listen: If you’re gonna experiment on yourself like this again... well, I can’t be responsible. I mean, I’m not knowledgeable about things like that. I’m not a doctor or anything.”

“It’s not only you. I also have --” He named a couple of his friends -- “and Dad.”

“Yeah, but I’m the one in the house with you; I can’t be held responsible in that way.”

But I tried. The next day I phoned him from work, asked how he was, reminded him to call Hannah about a hat he was crocheting for her, and that evening I made sure to invite him downstairs to eat with Devin and me. Bret kept interrupting us with what Cathy had begun to call “pontifications”. But at one point he suddenly said, “I don’t wanna LOSE you guys.”

“Then stay where WE are,” I answered, and he responded by not interrupting. But he seemed to be struggling. And shaky. Later I said to him “Bret, I don’t want you to wake me up tonight. I didn’t get enough sleep last night.”

“Okay. If I need to come down I’ll be really quiet.”

That same day the social worker from Inglis House had left me a phone message. “I hear there’s a possibility your insurance might not keep paying. We need to have a

meeting to discuss plans.” For a few days I was into denial about Bret. We all were. Now I can’t understand how I could have been, but I was. Thinking about it, I’m not proud. But I didn’t quite know what to do. Maybe some part of me believed that, as with my husband, this is how it was *supposed* to be, a person in that state was supposed to live at home, I was supposed to take care of him, a child of twelve was supposed to be living with a delusional brother. Maybe I believed that if I told a professional, that person would just say “uh-uh”, as had been my experience when I told professionals that Jeff was waking me up twenty, thirty times a night.

One early morning I found Bret in the backyard. He said he’d been there all night. He’d locked himself out, he said, so climbed around to the back and slept there, not wanting to wake us. “But that’s okay,” he added, “look what I spent the night making.”

It was a permutation of twigs and wires, not artistic at all. A little later, as I left for work, he said, “Be careful. Several people tried to shoot me yesterday. Yes, several people have been trying to kill me. Watch out.”

So then I knew. But I taught my morning classes before walking back home and phoning his doctor. The receptionist was concerned but didn’t say what, hours later, the doctor on call got back to me with. “He should be seen as soon as possible. This is serious. And if he won’t come in, call 911 and have the police bring him in.”

At that point Bret wasn’t home. I decided to call 911, just to stake things out. But the phone was dead. So was the other phone. I felt afraid in the house, with the possibility of Bret coming home and no phone to grab if and when I needed it. I kept on my coat, grabbed my purse and new Abstract Algebra book, prepared to spend some time on the

front porch. There was a phone around the corner and I was able to reach 911. The woman who answered was very nice. "When he comes home," she said, "call us and we'll come." I also called Marielle and Matt; they weren't home so I left a message, what was going on, and also that I probably wouldn't be able to watch Jack the next day, as I usually did, between my morning classes and Advanced Engineering Math in the evening. I also left a message for Cathy. "I'm feeling scared; I need someone here with me. When you get back, would you come over and... and be with me. And -- this is REALLY ridiculous -- the phone also happens to be out of order so you won't be able to call."

I sat down on the porch and concentrated on Abstract Algebra. At the same time I felt scared. When it got dark I had to go inside. Empty house. No phone. I tried to settle in.

Then the doorbell rang. It was Matt. Whew, now I wasn't alone. He wanted to phone Marielle so we went outside to the pay phone around the corner. And then we saw Bret down the street. Matt and I quickly made a plan. I'd call the cops, Matt would go inside with Bret, I'd go up to talk with Bret while Matt waited downstairs for the cops.

This time whoever answered 911 wasn't quite as nice. "It he's 18 years old, why's he going to a pediatrician?" she asked.

I was used to that kind of thing. "I meant his OLD doctor. The last doctor he saw."

"Oh. Well, he's still an adult. WE can't do anything."

"Well, again: I'm calling because his doctor advised me to call. She knows he's 18 and she still advised that."

"Okay, we'll send two people over, and they can decide what to do."

“Thank you.” I then went upstairs to talk with Bret, who’d gone up to his room. “Bret,” I said. “I love you. I want you to know that, and to keep knowing that.” Bret was receptive. We talked some more. Soon there was a knock on the door; I heard a calm voice saying “Police” and I heard Matt answer the door. Bret heard it too, and didn’t look all that surprised. I started downstairs and called out, “Could you wait just a minute?” Then I went back to Bret. “Bret, remember, I said ‘I love you’. I love you and I’m very worried about you, and also about Devin and me, so I called the police.”

He nodded, *really* nodded. He seemed to understand, seemed almost relieved. We went downstairs. “Could I just be observed for a few days?” he asked.

“Now, wait a minute,” said the male cop. “Nothing’s been decided yet. Now, young man, could you do me a favor and sit down on the couch and just be quiet while your mother tells us why she called us. You’ll get your chance to talk, too.”

Bret was like butter. He sat down and, though interrupting a few times, was easily shut up. I made what I had to say short. “I called you because, for the past few days, he’s been increasingly delusional and paranoid, and his doctor told me to call you.”

For the record, I believe most of what I hear about police brutality and I’m not a big believer in many of the ways in which law is enforced, in particular prisons and the death penalty. But these cops were like therapists. GOOD therapists. They must have had some big-time sensitivity training. Bret immediately took to the female cop. She knew a lot more than Bret about the holistic nutrition Bret had tried, and Bret immediately acknowledged that. He asked her questions about fasting and reached out his hand to her a couple of times. “I can see you KNOW me.” he said.

The male cop began to assess the situation. "To me, Bret, you look kind of unhealthy. You look gaunt, and you keep putting your dirty fingers in your mouth --"

"Go wash those hands," said the woman, with a smirk to me. Bret immediately went to the kitchen sink. Ten minutes later he was still washing and the woman mentioned this to me, this time with a serious smirk. "Well, Bret," began the guy, "you're eighteen years old, technically an adult. I can't make you go anywhere. But I have to say I'm concerned. I don't feel comfortable just leaving. I'm gonna go call my supervisor." After the supervisor had arrived he continued, "Well, like I said, we can't force you to commit yourself. You know, YOU can voluntarily commit yourself. Then you can leave when you want to, and you can get the attention that it seems to me you need."

"How would I do that?" Bret asked.

They gave us the names of some places. "Bret," I asked, "do you want to go to the doctor?" Bret nodded. "Okay, tomorrow morning. I'll call and make an appointment; they'll probably take you tomorrow afternoon. Okay? We'll go tomorrow, okay?"

Bret nodded. But as soon as the cops left he said, "They're the voice of Satan." Oh no, I thought. Aloud I said, "It seemed as though you LIKED them." "I did," he answered.

Children's Hospital is a mile from our house; we had to walk because the day before he'd given his only pair of shoes to a homeless person. On the way he babbled, "Don't let them see you", then something about being "in the red" and "in the blue". He kept looking right, left, up, down. At one point he suddenly announced, "I'm going home."

Gently I turned him in the correct direction. "No, I don't think so," I said, hoping that was the right thing to do. I later learned it was called "redirecting". "Oh, okay," said Bret.

I felt very tired and a little resentful that I had to be doing this -- and by "this" I meant, in part, getting somebody bigger than me someplace else, like Jeff onto the toilet.

When we arrived I breathed a sigh of relief. Dr. Ginzburg immediately took over and he handled Bret well. He talked *with* Bret, liked his hats, gave him dignity. I was almost afraid he wasn't seeing what was going on. But then he conferred with me alone, keeping his eyes on the door to the room where Bret was sitting. He handled *me* well, too. When I told him about Jeff and Kerin he said "I'm sorry." Then, "obviously Bret's 'way out there. He's as loony as a loony bin. I think he should go into Friends [Hospital] immediately. Friends is part of our system so insurance will take care of it." I breathed another sigh of relief. This was no "conspiracy of silence".

So, I wouldn't have to run a mental institution in my home, the way I had so recently run a nursing home. I felt like crying in wonder as he arranged for the staff to lend me the \$60 I'd need for a taxi to take us to Friends. "We're not supposed to do that," he said. "But we will." I thanked them profusely. During the taxi ride Bret suddenly took it upon himself to instruct the driver. It was almost funny. Right in the middle of Route 76 he said, "Okay, we're getting off here."

"No, no," I told the driver. "Just keep on going." Redirecting again. For a second I thought, what if the driver listened to Bret instead of to me? But we soon arrived at Friends and they took over too. Again I felt grateful to the point of tears. Bret seemed relieved, too. And I knew that, once Bret was taken care of, I'd make sure it would be my turn. I phoned Marielle and asked whether Matt's parents, who lived nearby, could

possibly pick me up. No, but his brother Greg could. “But maybe,” she suggested, “we should SAVE that for when we need to visit Bret.”

“Shit, no.” I thought. Aloud I said, “No, I need it tonight.”

Bret did not seem upset or nervous when I left. He seemed to know that he needed, maybe wanted, to be there, and that he was in good hands. When Greg arrived, he handed me a granola bar. When I got home I phoned my sister, then Cathy. Cathy came over and brought me dinner, my favorite “typical-restaurant-type meal”, chicken-salad sandwich on wheat toast with fries and a pickle. The next morning I phoned Jeff and told him that I just didn’t have the energy to visit him. I also postponed the Medicaid meeting with the social worker at Inglis House. Yes, I had long known how to take care of myself. And that was as good as it got during those years.

I also made sure to take care of the others in my life -- in particular, Devin. We were due to go see his friend Jade’s mom and her comedy improv group, “Just Kidding”. We did not cancel these plans. I told Jeff that I could visit him only once a week, now that I was working full time. Once I even had a mini-tantrum, during which I blurted out to him, “Sometimes I feel like disowning both you and Bret. I do not intend to disown MYSELF.” And when people asked me, “How’s Bret?” I’d sometimes say, “Right now I’d rather talk about how I am” or “Bret’s being taken care of. I’m the one who’s not being taken care of, who takes care of herself, and who’d like to have other people take care of her.” I was a little concerned about my spirit. It was a *human* spirit, I knew, and as such it could be broken. I tried to treat it well; perhaps sometimes I went overboard.

I had a morning teaching schedule so I was free every afternoon. But I didn't let on about that. I had no intention of visiting Bret every single day or spending hours on the phone with concerned friends and relatives, assuring everybody that everything was going to be all right, in particular that I was doing whatever I was supposed to be doing.

"Marion, you're so wonderful," said Cathy. "You're so RESPONSIBLE -- I mean, to YOURSELF." Bless her, she did not say, "You need to look out for Your Self Too."

Of course Dev and I missed and felt for Bret. He was suffering and homesick. He missed the cats. He just wanted to hang out in his old room. He cried. He phoned and left messages. "I'm just calling to say I love you guys." He was fragile, beautiful, adorable, lovable, and the Friends staff acknowledged that. But some people, when I told them about his calling to tell us he loved us, just said "u-huh". I resolved to, whenever anybody was having a crisis, be positive -- in the sense that if I couldn't be positive about the crisis, I'd be positive about the person going through the crisis.

I wasn't finding it at all hard to communicate with Bret. Yes, he still had some delusions, as the medication worked its way into him. "They don't like me here 'cause I'm Jewish." "There are people here who are spreading rumors about me. I'm not allowed to say who." But also, "How's your Drexel teaching going?" then, "You can visit me as often as you CAN. I know you have Dad to worry about." And finally, "I want to go home but I might not ever be able to."

I felt that I knew what he meant and I asked, "Do you feel safer here?"

"Yeah."

“Well, Bret,” I said. “When you get home I’m going to do everything I can to make things feel safe for you. That’s what the various rules we were talking about before are for. And also, you’re not going to be going out very much. You’re going to be hanging out in your room and with us a lot.”

“Yeah,” Bret agreed. “Ground me.”

“Yes,” I said, “you’re going to be grounded.” Bret’s social worker there thought that the “grounded” idea was a good one and I felt pretty confident that I was handling Bret well. But I still needed more affirmation and -- I admitted it -- praise. I knew I didn’t have the expertise, and the perspective, that the professionals at Friends had. But Bret and I had reached a point when I felt comfortable with him, where I no longer found him and any remaining delusions scary, though I knew Bret himself was still scared. And I had some Kafkaesque thoughts. Suppose Dev flipped out? Just as Bret seemed to be imitating his Dad, Dev could imitate Bret? Suppose I wound up having to take care of everybody, 24/7, not being allowed to keep my Drexel job, or to do math at all?

During this period Jeff did something for which he deserved a lot of credit. Dev and I were visiting him and Bret phoned. “Hi, Dad. Hi, Mom. Listen, there’s something I want to discuss with you. I really don’t like the food here and I’m thinking of signing myself out, giving 72-hour notice. I have the slip in my pocket and I’m thinking of signing it.”

Dev and I exchanged appalled looks. When I saw the same look on Jeff’s face I thought, “Thank Goodness”. I’d been worried that Jeff would agree with Bret. I said whatever I could think of. “Bret, I don’t think that’s a good idea.” “I think if you were

ready to come home, they'd have dismissed you." And finally, as a last resort, "If THEY don't think you're ready to come home, then we don't want you living with us."

Then Jeff got on. "Bret, listen," he began. "you know, I hate it here, where I am. But I know it's the safest place for me to be so I'm staying here." Thank Goodness! I thought again. Jeff had managed, this time, to overcome the forces acting on him.

Bret was at Friends for three weeks. During those weeks he wasn't happy about taking his medication, theorizing, as Jeff always did (and perhaps partially correctly) that it wasn't good for him. In actuality, it seemed there wasn't much choice, and Bret must have known that (though it took him over a decade to "forgive" me for "believing the doctors rather than me"). He took the pills without struggle and they drew him more and more into reality; eventually he could come home, though he'd be in a day program for a week and we were all strongly encouraging him to go into therapy. The diagnosis was "schizophreniform", (temporary) schizophrenic behavior without any real diagnosis. Bret also reminded us that he'd been fasting for six days. (How could I, his mother, not have known that? Well, he was eighteen, going about his own business, including meals, or non-meals. AND I was a well spouse.)

Having him home was a little scary at first. I was especially concerned about Devin -- first his father and now his brother. But it seemed to work out, and life gradually returned, first to half-normal, then to almost-normal; we all kept our eyes on Bret and I, as non-invasively as possible, kept tabs on his therapy appointments. We were told that, if a year went by with no further episodes, he probably didn't have schizophrenia. So we all began ticking off each day, each week, each month.

And how much of it was my fault? Probably very little, I believed. But “probably very little” wasn’t enough for my compromised psyche. I watched and judged myself during those months, and imagined myself judged by others. At Thanksgiving dinner, for example, I myself wasn’t terribly upset that, this year, the turkey came out a little dry. But it seemed that Marielle’s Matt was being a little too quiet. He’s always loved my turkey; I imagined his disappointment. And I could almost hear my parents, on behalf of their hero Freud: “Well, your turkey WAS dry. And Matt did expect gravy. Thanksgiving does normally entail gravy. You say you want a normal, non-downtrodden life? Then perhaps you should take your turkey a little more seriously” and finally, “Turkeys come from the unconscious.” (I laugh now but I didn’t then.) Perhaps my unconscious was inadequate, and that’s why my son was diagnosed “schizophreniform”, my husband diagnosed M.S., and my turkey diagnosed dry.

Life was no longer a matter of doing what we felt comfortable with or believed in. Home-schooling aside, we were wide open. It seemed we didn’t have the same rights as most citizens. Before this I’d been painfully conscious that if anything (further) went wrong, it could be my fault. And now something further *had* gone wrong. All my heroism in the face of Jeff’s M.S. was water under the bridge. We had lost our freedom, or whatever freedom we’d had.

Everybody, it seemed, asked questions like “Are the family therapy sessions really therapy or just discharge plans?” and “Did you get any names of therapists yet?” (even after I already had). It seemed they did not ask questions like “Do you listen to Bret?”

and “Does Bret say to you, ‘I have a problem talking to anybody other than you.’?” “ It seemed as though, if the answers were impressive, nobody asked those questions.

When there’s trouble, you’re suspect. It’s especially true when you’re a parent. When something bad happens to your child, you’re the first suspect, or so it seems to you. There are at least two reasons: (1) You were at the scene of the crime (meaning you’re with your kids most of the time) and thus (2) if you were not at the scene of the crime, you should have been. I felt as though I were, not on trial, but parole; family therapy at Bret’s Day Program felt like reporting for parole. You have to answer each question in 25 words or less. Sometimes it felt like worse than parole. Guilty or innocent, I had been convicted. Thank Goodness, I thought, there would be only two sessions.

The months passed. Bret continued to crochet hats, sell them, and consider the possibility of college. He started drum lessons again and took Ceramics at Fleisher Art Gallery. On his own, he phoned the psychiatrist that the Day Program had recommended and made his appointments. And I continued to teach full time at Drexel.

I was determined. A childhood memory came back to me. My parents took us out to Mother Hubbard Diner and the waitress that evening seemed snotty. She actually held her head perpetually up. “What a snoot,” said my sister and I. But my mother told us, “She looks like she’s not going to let anyone take advantage of her because she’s a negro.” Now I thought, no one’s going to take advantage of me because I’m unlucky.

In late December 1997 Jeff had developed a fever and was spitting out non-clear liquid. They were watching him carefully and I expected it would soon be hospital time

again. “Oooo!” said Normie, “Maybe this’ll be IT.” We both laughed, not nervously. Indeed I had come to that point.

I dreamt that Jeff wasn’t sick at all; he and I were having sex. Suddenly he stopped moving. “What happened?” I asked. “I got small,” he answered. Indeed he had. “You were going too fast,” he said. “I needed you to go slower.” In real-life he needed me to range him more slowly. And the sip ‘n’ puff wheelchair needed to be set on slow. ‘Way too slow for me. In the dream I had been going too fast for him, but not for me.

On Christmas Day 1997 Bret, Dev, and I were visiting Jeff’s parents. Jeff’s mother was in a pretty bad way. “I don’t like this life. I can’t go out or anything.” I listened, hoping she’d conclude something. But instead she said, “Oh no, I wouldn’t THINK of putting him in a nursing home.” She did not dote on her grandchildren. She had only rolls, turkey, and salami slices, no potato salad and not much mustard. She barely looked at the presents we’d brought her. Still, it felt like a safe place -- until the middle of one night, Jeff’s father woke up and called out, first “Hildy! Hildy!” and then “Marion! Marion!”

Jeff was using the suction tube more than ever; it made a loud noise, something I had somehow not noticed before. When I get old and sick, I thought, nobody will have any energy left for me. In particular, I won’t have energy left for me. The feeling of wishing Jeff would die was now sustained. But I also felt that, when he died, it would be awhile before I could feel relieved. In a couple more years, that last would no longer apply. There would remain only that burning wish, and the certain knowledge that, when it was granted, I would be indescribably relieved, even overjoyed.

I figured out a shorter way to get to Kronecker's Field Extension Theorem, so we managed to cover quite a bit of Abstract Algebra in those ten weeks. I thought of cool descriptions and metaphors for some of the stuff I particularly adored. About quotient fields and Kronecker's Extension Theorem I said "Mathematicians can just TAKE what they WANT. But then they have to watch out that what they take doesn't upset the the ALREADY EXISTING apple cart." The department assistant head told me, "The fact that you're able to get students interested in abstract algebra says something good about YOU." Despite that I was later told that auxiliary faculty like me would not be teaching advanced subjects like Abstract Algebra; that had to be done by tenured and tenure-track faculty. "Which is a shame," she added, "because they don't particularly WANT to, and you do." From then on, though, I was considered "the abstract algebra person." Abstract students would be sent to me with questions, rather than to their regular professor, and once I was assigned an abstract algebra independent study. I was also given the job (In lieu of one course) of running the tutoring center, "because the students seem to like you so much". We had a special event for the "opening" of the center, and I was sort of the guest of honor, getting to make a quick speech welcoming everybody. Yes, I was really enjoying my new job, and apparently vice versa. And now that I was making full time money, I could fulfill one of my current dreams during the upcoming summer and take, besides a week in Rehoboth Beach with Devin and his friend, a ten-day "real vacation" by myself.

In March of '98 I did another reading at one of the Columbia-Presbyterian medical conferences in New York. Devin came with me and we both stayed in Roberta's loft.

One evening her phone rang and it was for me. It was Marielle; that morning Jeff's father's home health aide had arrived to find Jeff's mother wandering around the house with a gash on the side of her head. Jeff's brothers had been contacted and had called the doctors, set up a schedule whereby someone was always there with them, and eventually hired somebody until... well, until they could both be placed in a nursing home.

Marielle was upset, whereas I was relieved and not surprised. I'd known that's where they belonged. But Marielle was full of more things to do, some of which had already been done. Call Jeff's brother. Call the doctor. Call the nursing home. Go see about the house. And don't I want a car so it would be easier for me to go visit Jeff? No matter how much or how little I said, Marielle asked, "What's a MATTER, Mom?" A classic case of projection, so it seemed to me. She was young and upset; that was probably normal. I, however, felt older and wiser, if blunter. I decided, pretty much on the spot, that I would visit them in the nursing home as little as possible. I knew I'd had it. The way "a woman knows these things" when it's time to stop having babies, so *this* woman knew *this* thing. I knew Marielle might not understand, nor other people involved. I decided that I was willing to be thought badly of.

Another new era, new in a good way, almost began during my Drexel years. A "rep" from a very big textbook company came to visit the profs in their offices, asking not only what books we'd like for our courses, but whether there were any books we might want to *write*. "I'd like to write a user-friendly calculus text," I said and proceeded to de-

scribe my ideas. He was very interested. I wound up writing up a prospectus -- Table of Contents, Introduction, two sample chapters. "Calculus among Friends" would be the working title. I hired one of the Drexel secretaries to type it up in Word and as quickly as possible I sent the floppy disc to the rep. He wrote back that he and his cronies were interested, and would soon be sending it off for review by two or three peers.

But then just as suddenly I was told that the main gun there had changed his mind; now he was interested in possibly using my book as a calc text for business students. And then I never heard from them again. When I phoned or emailed my rep, there was no such phone number or email address; he was no longer with them, I guessed. Yes, I followed up on it. Years later the main guy there told me, over the phone, that they weren't interested in user-friendly calculus texts. Several years later a similar thing happened with another publishing company.

A couple of months ago (December 2006) I wrote, for MAA Online, a review of "The Complete Idiot's Guide to Calculus". For what was probably the first time, I wrote an uncomplimentary review; in essence, I liked the user-friendliness of the book but the author made 'way too many serious mistakes, and didn't really seem to have much calculus or math insight (nor true love of math). What the review did for me was affirm that the world really does need a user-friendly calculus *text*, meaning a real math book. And so far, to my knowledge, it doesn't have one. "Calculus among Friends" on my shelves and in my computer doesn't count. Of the several things which I believe I have to offer the world, I'm glad that some were taken. Of course I wish that all were, but I'm not through

yet! Right now I'm embroiled in other projects, but I'm not forever giving up on "Calculus among Friends".

Back to 1997: Bret continued to be non-delusional. "Do you think that a lot of all this was because Dad's been sick?" I asked him.

"Yes," he answered. "Definitely. I've been sick a long time."

"Maybe," I said, 'since Dad was sick, almost all your life, and all the TALK about Dad being sick, maybe it just seemed like EVERYBODY was sick -- you too."

He nodded "Yeah, maybe."

Just a tad more, I talked with Jeff about how I didn't know whether I'd be able to "keep doing this". Of course that was hard on him. "No more visits?" he asked poignantly.

I shrugged. "I don't know. I just don't know." He also said, though pleadingly, some manipulative and predictable things. "I thought we'd always be there for each other." "I'D always be there for YOU." And especially (his trump card), "I've been supporting you all these years."

Once again I answered, "I'VE been supporting YOU all these years, too" and "It doesn't give you the right to my life." I did not say "I don't need you to support me any more. Now I'm supporting myself, and the kids", or (infinitely more painful) "Really, Jeff, I thought you'd be dead by now."

CHAPTER VIII: AGAIN

“What’s suspicious about the real numbers?” was how I began my Complex Analysis course. (Two answers: There’s no square root of -1 . There’s no arcsine of 2 .) I was excited about that. I also had spring fever. Out in the square with Dev and Cathy I fantasized having a lover. A string quartet by the fountain played Beethoven. The sun made yellow all over. At Drexel, too, “the Quad” had its benches, grass, and yellow sun.

Soon it was May 1997. My first year at my new job was drawing to a close. I was looking forward to summer, which would include my ten-day New York vacation. I’d specifically planned it to include two weekends, since that’s when the flea markets are. I’d spend my days walking around Soho, maybe visiting my sister and Nancy, who’d moved to New York. But mostly, this first adult vacation I wanted alone.

Suddenly Devin and Jeff were bonding. Jeff would phone home and ask specifically to speak with Dev, and Dev was glad to talk with him. Once when we visited Dad, Dev brought along a painting he’d made; he also played Fur Elise for Dad on the piano in the downstairs lounge. Later, privately, waiting in the lounge for Dad to be put to bed, Dev said, “Dad really seemed to like my piano playing. But I don’t think he liked the picture.”

“Why? ‘Cause he didn’t say anything? But you know how Dad sometimes is...”

Later, though, back in the room, “Dad” asked about the picture, “Can I have it?”

”Sure,” answered Dev happily.

The Star Ledger article had said Jeff had four clocks in his room. He also had three thermometers. There was one not yet hung up, and for some reason Devin liked it. Jeff winked at me as he told Dev, "You can take that one home." Dev talked about plans to carry the thermometer around with him and measure the temperature of everything. He put it on his keychain, even though it was almost a foot long, and then, since the hole for hanging it was half an inch in diameter, he put it on his finger. "See my new ring?"

On the bus ride back Dev talked about the new picture he'd make for Dad. Also, how he could use that thermometer for a treasure hunt. "Go where the temperature is so many degrees..."

"It's really important to you, isn't it?" I said, "that Dad liked the picture."

"Yeah."

On June 8 Marielle and I went to visit Jeff's parents in the nursing home. They weren't themselves any more. And I felt afraid that Jeff's father would ask me for something big, not just push his wheelchair forward or open up the milk carton, but feed him or wipe his mouth. Jeff's mother was no longer in reality. "Oh, I see Jeff every day," she kept saying, and about Jack she told Marielle, "You're as good with him as though he were yours." When we told her we'd have to leave in an hour, "Oh," she said, "you're not sleeping over?" During lunch she kept handing me the tops of containers. They don't belong in the middle of the table, she decided. That must, I thought, come from a lifetime of worrying about things in their proper places. What will I do when it's my turn? Pick people up and put them on toilets? Try to adjust respirators? I hope I'll solve equations. Meaningless equations, with meaningless solutions, but equations all the same.

As we were leaving Jeff's mom said, "And YOU, Marion. YOU I miss most of all." We had been close. Getting that way had been easy, from the moment Jeff had first brought me into their kitchen to meet them. It hadn't been long before we were shopping together in Daffy Dan's and I wanted to call her Mother. Later she told me I was the one she could talk to most. Of course, I missed her, too, but the her who could shop and talk. Her sweetness was still coming through but, right or wrong, that wasn't enough.

Jeff's dad still called "Hilda!" and that upset me. They'd been placed in the same room. When they lived home, during his illness, they hadn't slept in the same room. Now, though, he was probably waking her up. "But she doesn't do anything for him," Marielle assured me. "She's completely out of it." I wasn't sure. Jeff's mom sported that worried look. She'd just stand there when he called, as though wondering what to do.

I was counting the days, and the tasks. Five more classes, finals, root canal, and I'd be a free woman with a salary. And then something terrible happened. I still consider it the most Kafkaesque thing that's ever happened to me. I brought in my Drexel grades -- I'm sure I brought them in; I still remember details about that, counting the sheets, handing them to the secretary, noting that I had the grades to both courses, thinking, "I am hereby handing in my grades." And the Calculus grades, a few days later, were missing from the department's records, the administration's records, and my office.

I have various policies that I never deviate from. I never take my wallet out of my purse. When I have to take out money I keep my hands and the wallet inside the purse. I never stop holding my purse, except at home or teaching. And I never, unless I'm actually grading papers, take them out of my briefcase. I also never grade papers any-

where except in my office or home. But this one time, for some reason, I hadn't xeroxed the grade sheets and taken copies home.

I can't fathom what could possibly have happened to those papers and those grades. If, perchance, I remember incorrectly about handing in the grade sheets, the papers would still have to be either in my briefcase, my office drawers, or home. And they weren't. I kept looking. If, somehow, I made a mistake and put them in the trash, they would still be there because the trash hadn't gone out since I completed the grades. The only thing I could think of was, they were stolen -- from, yes, my office, the department office, *and* the administration office. I was not the first one to think of that.

That was the very-first time I ever lost a set of papers or gradesheet or anything involved in a teaching job or any job. So I kept analyzing. Why would only one set of grades be missing? And why would students steal the Calc I grades, when most of them had gotten A's? I've never found out. It didn't matter as far as the job was concerned. I had, still have, a very good memory; all I needed was a class list and I could remember every single grade. So things were quickly taken care of. But I still wonder.

Every teacher, every doctor, every working person has a failure or two. And the year being what it had been -- Bret's psychotic episode, the Jeff-stuff -- I should be glad that's all that went wrong during my first year at the job. At the time, though, I hoped I wouldn't spend the summer worrying -- that, for example, a student would ask to see her exam paper -- the summer which I already was feeling rather protective of.

On our beach vacation it seemed the kids were constantly wanting to spend money. I'd forgotten that's what vacation with kids means. They wanted rides, skee-ball, mini-

golf, and Thrashers fries every hour on the hour. And none of that took up much time. As for the one free activity, the beach, I had my own feelings about that. It always takes me time to get used to the water, both the cold and the waves. I don't like breakers; once I get past the breakers into the calm, that's great. But again, that takes time, and courage. Courage like life-courage, courage I needed a vacation from.

Walking the boardwalk was nice. But the kids wanted to stop into the arcades. More money. On the second day we came back to our apartment to drop off heavy towels; Jade took a shower; Dev and I lounged on the couch. He seemed quieter than usual. "I want to race in and do everything," he said.

"You might have the vacation blues," I said. "Huh?" he asked. "That's when you're on vacation but you begin to realize that life still goes on." "Huh?" "Ya know, life. Just regular life. Your life, and your self, doesn't go away. And you might, at times, not feel quite as happy as you think you should."

"Huh?" But he moved closer to me and soon said, "I don't feel so good."

"Do you feel hot?" I asked. "Does your stomach hurt? Do you mean you don't feel HAPPY?" "Yeah." He paused, then "I keep asking for so much and then I ask for more."

I melted. "That's the vacation blues; that's what I meant. And don't worry; you're acting perfectly nice. It's just... maybe it has to do with growing up. But I have to WORK at taking a vacation. When I take a vacation, I'm not trying to escape my whole life, just some things. Like teaching, cleaning the house, having to visit Dad... you know, responsibilities. But not writing, not math. I have to decide what I'm trying to escape and how much math and writing to take with me. I have to decide just HOW to take the vacation."

I don't remember whether I actually said all that; maybe I got carried away just now. But soon Dev was off the couch, doing stuff with Jade, free stuff. After a while we went out again, browsed in the bookstore, played a little skeeball, got another round of Thrashers, came back, ate nachos and salsa. I like to think that, by describing things so much, I helped define things for Dev, helped him sift and place things. I like to think that's what helped him and Jade finally settle into a really nice vacation. But now I'm thinking that, in time, they might have settled in anyway. Also, maybe I overdid it, maybe even talked Dev into feeling sad. Maybe he was simply tired.

You've probably noticed that I did that a lot. I hope you've also noticed that I usually knew when to shut up. I certainly understand why I was like that, so often explaining and describing. I had a lot of things to explain and describe -- a lot of breakers to get through, what I called "homogenous chaos" to get knocked about in, before we could settle into the deep calm.

A few days after returning from Rehoboth I'd be taking the New York vacation I'd so been looking forward to, and getting worried. Afraid something would happen, something involving Jeff, Bret, or the lost gradesheet, Bret. My vacation seemed at risk. It didn't help when, the day before leaving Rehoboth, I got a phone message from Marielle. She and Matt were on vacation. "I know you're not home," she began, "but I just wanted to say that we arrived, we're having a great time. I hope you guys are too. And also --"

My ears, mind, and heart perked up at that. "I talked to Bret and I'm worried; I don't like the way he sounds. Arrogant." I immediately called and spoke with Bret. I didn't feel

that he sounded especially arrogant, but I also didn't discount Marielle's message. And then, a few hours later, my sister phoned. Marielle had phoned her from Ireland and asked whether she could call me and discuss Bret. Rosalyn sounded a little hesitant. "I feel a little funny calling," she began. I appreciated that.

It all got me calling Bret's shrink. I told him what Marielle had said and how I felt. And -- hurray! -- Bret's shrink agreed with me. Bret was not arrogant or spacey, he said, "although he does have a way about him. But he's definitely not clinically depressed. I'm pleased that he's so communicative with you, showing you his hats, telling you things, in particular about his drumming." He was likewise pleased about Bret's communication with his brothers. He added that all that did not seem to be masking anything. There was absolutely "no danger" that "the October incident" would happen again; it was due to fasting and had "nothing to do with the present or the future". Best of all he said, after I'd asked, that it was definitely okay for me to go away on vacation.

I arrived at the small hotel on 11th Street just west of 5th Avenue, dropped off my suitcase, then went to get Manhattan's biggest Salvation Army out of my system. I bought lots of black clothes, had Sri Lankan food, then came back to settle into my tiny comfortable hotel room, really more like half a room but with TV, air-conditioning, and sink. Over the next ten days I walked streets, some familiar, some not. I stopped in bookstores for hours, saw movies, took part in a Messiah sing-a-long in July -- only in New York! There was also a Brahms Requiem sing-a-long, and Mozart's Mass in C Minor. I visited Nancy and ran into Freda at a 96th Street Salvation Army; we wound up thrifting and supper-ing together. I did not call home every day.

On the next-to-last day I walked down Broadway again, detoured into side streets, saw spiffy furniture stores and the Soho Guggenheim Museum Shop. I also stopped into Shakespeare and Co. and came upon "The Man Who Loved Only Numbers", about Paul Erdos, the rather eccentric mathematician who'd died recently. I read about half that book and wanted to review it. Jet Wimp at Drexel had told me that one of his summer plans was to review a book about Erdos; I didn't know whether it was that same book. I decided I would ask.

The next day, as I prepared to leave my vacation, I felt strangely happy. Or maybe well rested. Or relieved that the vacation had been successful, and possible. Soon after arriving home I phoned Jet to ask which Erdos book he was reviewing, telling him how intrigued I was by the book I'd seen. "Ya know," he said. "I'm a little over-extended; I just finished two other reviews. So if you want..." I did want, and that's how I became a reviewer of math books -- another unpaid career, but a good "lateral move" as well as opportunity to air some of my beliefs about education, life, and math.

On Sunday I visited Jeff. That night I dreamt about a suitor literally chasing me. In their room at the nursing home Jeff's father was continuing to bother his mother, calling out to her at night. She looked bad. Marielle, Jeff, and I wanted to arrange things so they had separate rooms and the staff was more than willing to consider it. But Jeff's brothers said no. They said sentimental things like "They're been together all these years; they shouldn't be separated now." In vain did I point out that, in recent years, they had not shared a bedroom. "Our hands are tied," said the staff.

In the elevator at Inglis House the wheelchair behind Jeff had to get out first. For

some reason Jeff wouldn't get out of her way. "Jeff," I kept prodding. Then, again for some reason, Jeff started to maneuver around inside the elevator. First, it seemed, he tried to get to one side and then, saying nothing but sporting a kind of determined expression, he made the wheelchair go diagonally across the elevator. There was no way the woman could get out. I had the feeling that Jeff, physicist-style, thought he had some kind of innovative solution. A staff member was around and she knew exactly what to say and do. "Okay, now, LISTEN," she began, "in order for the person behind you to get out, you need to get out first." Enunciating loudly and clearly, she gave him directions. "That's right, forward. Now back up a little." Jeff responded. Nothing like that had happened before but it did happen again, increasingly.

I wasn't any more in the mood for our anniversary than I'd been the previous years. But Marielle met us at Inglis House, specifically for the occasion. She'd brought chocolates for me, and for Jack. I was relieved that she didn't rattle a spoon for Jeff and me to kiss. What is everybody so afraid of? I thought. I was so very willing to let go and nobody else seemed to be. On the bus ride home Marielle said, "Oh, by the way, I ran into Relli the other day. Boy, does she look terrible!"

I made the mistake of saying to her, "Yeah, I know. She really does... and right now I DON'T NEED friends like that. I don't need more of that kind of thing in my life."

Marielle was shocked and upset. "Mom..." she scolded.

I felt like a bad little girl. "I mean," I tried to explain, "you know... with Dad and all..."

"I'd expect you to associate it with Dad, but I also thought you'd feel bad for her."

Because I knew that I was not a bad girl, I defended myself. "OF COURSE I felt bad

for her. But this has been going on a long time.” I felt hurt; Marielle had known me all her life; did she think I wouldn’t feel bad about a friend whose health was going downhill? Now I see her own torment; I think I see what she was fighting. I should have said first how bad I felt for Relli, and then how hard it was for me.

Jeff would often phone Devin with things that he, Jeff, was worried about. “Have you fixed the internet yet?” “Chanel 12, 9:00. Program on American history.” One could say it showed caring, but it didn’t show knowing. It certainly didn’t show knowing *Devin*. Dev was interested in neither fixing the internet nor American History. Poor Jeff was anxious to be a good father, but the way he was going about it wasn’t working.

And then began premonitions of more trials and tribs. One early afternoon Bret came in to chat. He looked thin and gaunt, and he said weird things. Plans to become a homeopath and cure dad, ideas about diet and, when I pressed him, worries about his own health. “I shouldn’t stay more than ten minutes in the sun,” he said, copying Jeff who couldn’t spend more than ten minutes in the sun, for fear of getting over-heated.

“If you’re so worried about your health,” I said, “maybe you should see your doctor.”

“Would he see me, not in his office, but out in the park or something?”

“No,” I answered. “I don’t think so -- unless you paid him for traveling time.”

“No, I won’t see that doctor; I know other doctors; I’ll talk to them. Mom,” he added, “I promise I won’t do to you what Dad did to you.” I made a mental note to phone Bret’s old shrink. But what I really felt like doing was telling everybody, “Look, YOU just go ahead and do what you want. I’M going on with my life.” I felt like adding “Sorry guys, I can’t help you.”

CHAPTER IX: FLORESCENT LIGHT AND STATIC

This time I was spared the grueling task of taking Bret first to the doctor, then to the mental hospital. This time the cops found him, around noon the next day, wandering, flailing, crying, beating his head against the ground. I'd been at work and poor Devin had been the one, home alone when the cops dropped off Bret's huge bagful of hats.

This time it was florescent light and static, and how they used to employ cotton to induce abortion so he wouldn't wear cotton. "I'm not paranoid this time," he told me, "but could you please call up Town Watch and have them watch our house." He paused. "Well, I'm paranoid but I'm not delusional."

Also, this time the mental hospital was closer to home, only twelve blocks away. But the diagnosis was actual schizophrenia, not schizophranaform, because it was the second episode. But he was, again, neither hearing voices nor seeing things.

Marielle was more adamant about her worry concerning Devin's home-schooling. She acknowledged that he was doing very well but she felt he needed a more normal life. I told her that I, too, had been thinking about that, and had in fact asked Devin whether perhaps he'd like to try school that year. He'd said no and Marielle said, "That makes me feel very relieved."

But not relieved enough. She'd just feel less worried, she continued, if Dev were going to school. How will he learn to write papers? How will he learn to get along? How will he get into CAPA, the creative and performing arts high school he'd decided he wanted to go to when the time came? I had good answers to all her questions but was tempted

to send Dev to school just to make Elle feel better and stop bothering me. At the same time I realized that, at that moment, circumstantial evidence was very much against me.

Bret was doing well at the hospital, though. Todd Caranza, one of the doctors, specifically told me that. After a few days Bret usually made sense when he talked, and seemed aware whenever he did not make sense. One day, though, he was wearing damp clothes, meaning clothes that he'd dipped in water and rung out. His explanation was that it was healthy, although he also said he felt cold.

"It seems like Bret's trying to take the attention away from me," said Devin. And so I tried even harder, got busy painting the walls and floor of the cellar room that he'd chosen for his bedroom. Jeff was supportive during this period. "Good work!" he said. "You're doing a great job." Cathy, too, was supportive. "The reason Devin's doing so well is YOU," she said, "and the reason Bret's been able to talk about his feelings is that you've always encouraged him to." But my spirit was waning. I often felt afraid that I wouldn't be able to write or do math, but in fact I finished the next-to-last draft of the Er-dos book review and did some actual math. I was specifically reassuring myself.

Different professionals said different things. The nurse said Bret wasn't doing very well and, like M.S., schizophrenia is progressive. Dr. Caranza said he didn't believe Bret had schizophrenia and, if treated, it's not progressive. "You have a wonderful son," he added. I chose to believe Dr. Caranza.

One late morning two weeks later Dev came home from walking around by himself, an activity he had come to enjoy since he'd been old enough to be allowed it. He was in a strange mood. "I was just thinking about how life IS and... it didn't seem so good."

I remembered how I'd felt at thirteen. Kind of existential. One early-evening I'd felt weird; my mother had put me in her bed. I wasn't sick; I just needed to be lying in her bed. Still, something prompted me to ask Devin, "Ya wanna go to school?"

"Isn't it too late?" Dev asked. "Didn't the school year already start? Do I KNOW enough?" So I understood that it was school time for Devin. "Of course you know enough," I answered, "and I don't think there'll be any problem in starting after the school year's already started; people do that all the time." The next morning we showed up at the Greenfield office. The woman behind the counter was a parent whom we knew from hanging out in the Square. "Oh, is Devin going to SCHOOL?" she smiled. "Oh, Devin! We're glad to have you."

So Dev started in on his new adventure. He now describes that first year as very difficult. However, his teacher at the time told me he was amazed at how "social" he was. (To which I replied, "Well, we didn't spend our lives within four walls. We had a home-schooling support group and Dev had lots of friends. We were more COMMUNITY-schooling than HOME-schooling...") Towards the end of that year his class took a week-long trip to Florida. Dev was excited to go and when he came home, school and peer-group life were a totally different ballgame for him. Apparently, on that trip, many of the kids had bonded and he, Jake, and Peter had formed a threesome.

I phoned a support group for parents of people with schizophrenia and Joe Fried, the contact person, told me, "Schizophrenia seems to present when the person is trying to make the transition to adulthood." I noted that and it turned out, at least in my perception, to be one of the most helpful pieces of information I got.

One day, upon arrival at Inglis House, I was feeling sick, tired, with a sore lower back. Jeff couldn't handle it that day. First he asked what I was so stressed out about. Then he said he'd done a good job of supporting me. Then he said that Marielle had it harder than me, having to work full time with a baby. Jeff then changed the subject to how Bret was doing and I said to him, "It was a good idea to change the subject because otherwise I would have walked right out this door." I thought how he didn't feel tender towards me. I was becoming aware of couples on the street, out together, enjoying being together. How nice that must be.

I made phone calls about various options for Bret after his hospital stay. Todd had found "the Ranch" in Vermont. They grew their own vegetables and cooked their own meals; it seemed perfect for Bret. He could try it out for 24 hours, free of charge, but then he'd have to decide whether he wanted to stay. Insurance would cover half the first month, and my Aunt Faygie would pay the rest.

But Bret's attitude about "the Ranch" wasn't what we'd hoped. He felt negative about *any* place; he wanted to remain in Philadelphia and get his own apartment or stay with his friend Rasta -- none of which felt very feasible to us, given his condition. I had told him he wasn't welcome to come home without following some program; I could not run a mental hospital as I had run a nursing home, and Devin certainly couldn't. Bret agreed to try "the Ranch" for at least a day.

"Todd" told me he had a theory; perhaps Bret had "learned schizophrenia", due to the illness, obsessions, and personality defects of his father. In general, Todd gave Bret and me a lot of his energy; he was wonderful. In fact, he volunteered to be the one to

take Bret to “the Ranch”; that would preclude any “power struggle” between mother and son, and relieve me of at least something. I also had decided that, as Joe Fried from the support group had said, Bret might fare best if he were to begin the transition to adulthood by traveling to “the Ranch” with Todd rather than me. However, the hospital rules prohibited that so I made train and hotel arrangements, decided to make it a sort of vacation for me. nice meals in Vermont and shopping in the neighborhood of “the Ranch”.

The train ride was uneventful. Bret was a little shaky and restless, but medicated and not uncontrollable. On the ride he said things that seemed positive. He was scared, he said, but he knew the Ranch was the way to go. He was going to get his life in order, do what he had to do, sell hats at the Ranch and in town. “Thank you, Mom,” he added, “for being there for me; if you think the Ranch is what I should do, you must be right.”

At our motel he slept straight through the night and after breakfast somebody from the Ranch came to pick him up. “Should I go along?” I asked.

“Either way,” the guy answered.

“You can stay here,” Bret said. “Have a good time in Rutland.” I decided -- correctly, I hoped -- to follow Bret’s lead. The guy dropped me off at the Rutland Salvation Army, Bret took my hand, firmly not desperately, and the two of them were off. I had no qualms; the guy was nice and I had complete confidence in the Ranch. I proceeded to have fun at the Sallie, even though it wasn’t a particularly good one, and then in the main shopping area of Rutland. Around 1:00, as had been suggested, I phoned Bret at the Ranch and yes, he was having a good time and no, he wasn’t planning to stay. And

yes, I was wise enough to not take him too literally, to calmly say “Okay, Bret, it’s your decision. I’m glad you’re enjoying yourself. And have fun making cider!”

At 4:00 I phoned again -- as suggested. I decided to first talk with Pam Grace, the director, who confirmed for me my various insights. Then I talked with Bret, who had finished the cider he’d help make. “Is it better than Zeigler’s?” I asked. Yes it was. That evening Marielle phoned me at the hotel to see how things were going. “And Pam Grace felt you did the right thing by not going in with him today?” she asked. Gee, I hadn’t even thought to ask Pam Grace that. O well.

The next day somebody from the Ranch picked me up at the hotel and brought me there to partake of their delicious homemade lunch and to meet with Pam and the rest of the staff. With the help of Todd I had already thought of things to convince Bret to stay. “Bret, you said you didn’t want to wind up like Dad. And one of the negative things about Dad is, he often lets fear be his main motive and takes the seemingly and temporarily easy way out. He didn’t have that ‘vital force’, that courage, that... well, that YOU need right now.” “I’ve already told you that coming home is not an option -- and wherever you go, it will not be something that I’ll want to put my energies into. I’ll be invested in a different way. You just might get MORE attention from me if you stay here, rather than in Philadelphia.” “You have a responsibility to help yourself -- and that responsibility is also to OTHERS.” “Remember, I’m your mom, and I know what’s best -- that’s what you said.” “You’re lucky to have the Ranch, and your support system, including me.” “Are you homesick? Scared? Is there anything the Ranch can do to help with that?”

I wouldn’t say it all. I’d say only what was necessary. At our meeting Bret began by

trying to bargain. "Can I stay another day?" "Nope." "Another week?" "Nope." "Two weeks?" "Nope." The commitment had to be for a month and, after a few more attempts, like "Who runs this place anyway?" Bret agreed to try it for a month. It was a great relief; I was conscious that, as a sort of reward, I'd get five whole hours on the train by myself, maybe another nice dinner, then an hour and a half more on the train from New York to Philadelphia. Then I'd "report" the success to Jeff, Marielle, Todd, Cathy, and Roz.

I got home around midnight. Cathy and Dev were waiting for me. We had a late supper of leftovers, as I told what there was to tell. Jeff called; Marielle had told him "the good news" and I filled him in on some more details. We were all exhausted, especially me. Then the phone rang again. It was Bret. "Hi, Bret!" I said warmly, realizing that he just might need to talk with me at this time. "Long time no see! How are you?"

"I'm fine," said Bret. "I've changed my mind. I'm coming home Saturday."

How I handled it? Pretty admirably, I think. "Well, before Saturday, make sure you talk it over with Pam Grace. How was your day at the Farm TODAY?" How I felt? For the first time ever I thought, probably I shouldn't have married Jeff or stayed with him.

We'd all hoped Bret was just bluffing but that Saturday he left the Farm. They kindly (with my money) put him on the train and he made it home. He went to live with his friend Rasta and his girlfriend; the two planned to "nurture" him, provide him with a room, food, friendship, and space. Bret phoned to let us know he was safely back and he phoned often after that. He was making hats, he said, and playing his drums at The Last Drop.

I soon visited him at Rasta's; he seemed fine and in good hands. In a sense, he was in a situation like the Ranch; perhaps the course he'd chosen was the correct one. I've since learned that in some European countries they treat schizophrenic people differently from in the U.S., after the initial drug treatment they "nurture" them, let things be worked out in their minds. I called Todd a few times and he assured me I was doing the right things, in particular in telling Bret that he was not allowed to visit us. I would meet with him, phone him, and continue to be there for him, but I didn't feel comfortable having a diagnosed and untreated schizophrenic person in the house.

At my sister's suggestion I decided to go into therapy again. I probably didn't need therapy as such -- I had "completed" therapy years ago -- but my life was so stressful not dire straits but 'way at the top of the stress chart. We knew that I needed the support, if nothing else, of a professional. The therapist I chose gave me just what I needed, and nothing that I didn't need, starting with "You should know that I read your book and I want to make sure you're comfortable with that. And the book was great." She gave me affirmation, credit, and at one point later on even said, "we really have to be honest here. You're MORE than an adequate mother." Over time she helped me gather strength, wisdom, and some strategy to leave my marriage. Many details -- dirty and clean -- will follow.

CHAPTER X: MOVING RIGHT ALONG

Being the mother of somebody who's ill puts you in a funny position. You're the one in control and everybody else isn't. It's frustrating to them, not being in control; no matter how you handle it, they like to feel they'd handle it differently. And better.

There were many misunderstandings. For instance, they seemed to think that I felt Bret was doing better than he actually was, and then they proceeded to act as though I was into denial. "Ya know, Bret doesn't sound all that bad," I'd say. "Oh, I don't know," they'd counter. "I don't like it." Or "Yeah, but how long will it LAST?" As though I didn't know all that. And as though they didn't trust me. What did I have to do to prove to them that I wasn't naive or negligent, that optimism rather than denial was what I was into? Will I have to re-learn the art of tantrum-ing? I asked myself. I truly didn't want to.

In contrast Todd said to me, "I know you'll know what to do."

I let some of it out. "But suppose I make a mistake?"

"Oh, you will," he answered. "Of course you will."

At the next Well Spouse Convention Fern convened a Divorce and Separation Workshop. It was well attended. Many attendees seemed to feel the way I did; they wanted out. "I want to get my life back." "The way my life is now, I don't see any reason to get up in the morning." "Suicide is an option; divorce is better." "About that 'til death do us part' bit -- what about death of THE MARRIAGE?" They said it; I didn't!

Various obstacles stood in the way of separation or divorce -- money, guilt, fears. One woman said, "Even in the well spouse community, I feel I'll be frowned upon." In-

deed. Here we were, having all these cool workshops, but in the more prestigious presentations -- in particular, the keynote addresses -- the stance was clearly that we care givers were all doing a *wonderful job* of care giving, we should be recognized and supported (even though not rewarded), all under the assumption and condition that we *continue* to be care givers, continue to “do a wonderful job”.

How did they know how wonderful a job we were doing? Did they come into our bathrooms and watch how skilled we were in doing toilet? Also, there was seldom any mention of what I called “the right to quit”. Society, I believed, should work towards giving us that right; social workers should try to incorporate that into their work with care givers. Sometimes this is unrealistic, or the caregivers themselves freak out when presented with it, but professionals can learn what to do. The mindset should be “right to quit” -- throughout our well-spouse odysseys, culminating at the point when it’s *time* to quit.

I learned much from that workshop. First, I learned that my own reasons for not yet quitting included Jeff’s passive-aggressive-denial refusal to acknowledge the situation. He acted as though it was just assumed I’d stay with him for the rest of his and my life. “That wouldn’t have gone over very well with ME,” said Antonia. “I probably would have responded by not loving him.” And indeed, that’s what was happening with me. Another thing I learned was that I felt the opposite of many of the other well spouses. Instead of feeling guilty at the prospect of leaving, I felt guilty at the prospect of not leaving. When I mentioned this in the Workshop, Joyce answered, “I have BOTH guilts.”

One midnight in October 1998 Inglis House phoned. “Jeff’s being sent to the hospital. He’s got a high temperature and he’s just not right. Usually he’s alert, asking for things

and all, and he wasn't doing any of that. He's not talking or responding at all. And he's foaming at the mouth. So we called the ambulance." Inglis House had never before talked about "foaming at the mouth". My first thought was "Hey, not YET. I'm ready for him to die but not YET." But my second thought was "Yes, yet." "Do you think I should go in?" I asked. "I think it might be helpful," they replied.

"To WHOM?" shrieked Normie the next day and we both laughed hysterically. Then I told her, "And you know the whole time -- and of course he got better -- all I could think about was that bouquet." Yes, remember Normie's and my bouquet?

Suzanne, my therapist, said "Gads, you must feel as though there are all these things IN THE AIR, and you have to be sure to CATCH all of them. And if you miss one..."

One day my sister phoned and asked, kiddingly, "Well, how are the DIVORCE proceedings?" We laughed, knowing they wouldn't happen just yet. But I had been moving more and more towards *separation*. I was talking to Jeff more sustainedly about my feelings, and sometimes more meanly. One evening, for example, Jeff phoned to say "I have a dentist appointment tomorrow morning, near you; would you like to meet me there?" "I can't," I blurted out. "I have morning classes, an appointment with a student, and Dev expects me home after teaching and...." -- here was a new thing -- "I have a LIFE."

Over the next hour I thought over what I'd said. So I phoned back. "Jeff, I was thinking, I probably wasn't very nice to you before. And I'm sorry. But I've talked to you before about how I'm really not sure I can go on with this, especially forever. I've mentioned it a few times and it seems as though you don't want to hear it. -- Well, OF

COURSE you don't want to hear it. But it seems as though you're not thinking, even a little bit, about what the kids and I are going through and what can be done about it. I think you need to do more thinking about that than you do." I spoke softly, calmly, and slowly -- beautifully, I thought. Not harshly, not desperately. No way was that a tantrum.

"Why do you have to CONVINCING Jeff?" my sister asked. "Why is it even UP to him?" In most ways, she was right. And indeed my therapist later told me, "You might have to leave Jeff WITHOUT his understanding why.". But I also knew that Jeff had power, financial power. I had to tread carefully. .

When I saw him the following Monday, he said, "So, I see you're in a better mood today." No, he had not gotten it. "Our love almost lasted forever," he said, later on in the conversation. No, he didn't get it. Our love did not almost last forever. In fact, there would be many years to come between the end of our love and when death did us part.

One day in December of '98 Bret asked, "Are there any conditions under which you'd let me move back in?"

"Bret," I answered seriously. "No." Bret didn't look upset so I continued, "I hope you understand this but it's because I love you. I think this is not a time for you to be living home; it's a time for you to be on your own, as you have been. I think you've been doing great and I think you can keep it up. I know it's scary and that's normal; it's scary to grow up and move on. But you're doing it, you're succeeding at it."

Being on his own had indeed worked well for Bret. Jeff and I had both noticed a good change in him. He was pursuing a part-time job (in addition to crocheting hats and drumming), no more problems with getting up in the morning. And he talked more posi-

tively about things, and about people. Even if he were to have another psychotic episode, I thought, the basic maturing would still hold.

Marielle, though, still didn't feel comfortable associating with Bret. She didn't come to Thanksgiving dinner that year. "I don't like the choices he's making," she said to me. "They're not HER choices to make" was the reaction of most of my friends with whom I discussed it. My sister also seemed to agree with me, but she also made the astute comment, "Maybe it's good for ONE person in the family to take that position." Yes. A little reality therapy. But then I felt bad that Marielle might have been *placed* in that position, as she's been placed in the position of eldest, only female "well child".

At our Thanksgiving without Marielle we all talked about the situation. I felt pretty seasoned about it all. But Devin said, "It was nice but it didn't seem like THANKSGIVING." I thought, "We'll all survive." As indeed we did. We were and are survivors.

At one of our therapy appointments Suzanne, who as a psychiatric nurse specialized in both chronic and neurological illness, told me that maybe Jeff had had neurological problems 'way before his first M.S. symptoms. That would make it before age 25, perhaps while he and I were first dating, perhaps before we even met. Suzanne used the term "frontal lobe". Sometimes, she said, the very first M.S. symptoms are cognitive, affecting insight. I thought back to what I used to call Jeff's "wishy-washy-ness", stuff he and I had had many heart-to-heart talks about but to no eventual avail.

I was almost 56. I still had only a few strands of grey hair, the rest thinning but ample light-brown with red tones in the sun. I still had high cheekbones and an aquiline nose. I was still tall and lean. One day I ran into an old calc student from the Temple days al-

most a decade ago, and she said, "You still look pretty." But I continued to have losing-my-purse dreams. There was a strain to them, variations on a theme. In one dream, although I'd lost my purse, I kept finding coins. A quarter, two quarters. Soon I'd have enough for bus fare, or more than one bus fare. Oh good, I thought; if I take the wrong bus, I'll be able to take another. I planned to go from bus to bus, live from mistake to mistake, keep finding coins so I could afford to pay for my mistakes.

Over the months Bret seemed to be doing well. He continued making hats, playing drums, and staying with his friends. After awhile we let him into our house and things were more or less normal, though we all worried -- sometimes audibly, sometimes not. Three and a half months went by. Then at 8:50 one Friday morning, the phone rang. "Mom, what're you doing now?" His voice sounded soft. "I'm feeling awful," he continued. "Sad. Depressed. I think I need to see a doctor."

I made a quick decision -- probably not the correct one, this time -- to make the responsibility be Bret's, not mine, or at least to see whether it *could* be. "Bret," I said, "how about if I give you some phone numbers and YOU call -- do you think you can do that?" "Yes," he answered. I gave him the number of his old psychiatrist (in case he didn't have it himself) and said, "I'll talk to you in five or ten minutes, okay?"

---"Mom, he was REACHING OUT to you," Marielle later said and she was right. But I guess I couldn't come through every single time.

"Elle," I told her, "I'm really sorry that you always feel I don't do things right. It hurts."

"Not ALWAYS," Marielle answered.

"No, not always. But very often."

“Well, I don’t want to bicker now..”

“No, I don’t either.”

Later Suzanne assured me that what I did *was* reasonable. But I still feel that it would have been better if I had rushed right on over to Bret, rather than rushing on over ten minutes later. But I didn’t, then, know that Bret had already slit his wrists.

When I got there I found that he’d been on the phone with somebody professional who was making sure to keep him talking. Now that I was here, though, we proceeded to take a cab to Jefferson. By the time we got there -- in fact, very possibly by the time he’d phoned me -- Bret was completely within reality. There were no delusions, and no paranoia. It was as though the episode had passed.

But it had been a very serious one. This time the schizophrenia, or whatever it was, had manifested, not through delusions, paranoia, or psychosis, but through extreme depression and suicide attempt. Bret told me that he had truly wanted to end it, to “go to sleep forever”. He had not felt that he was, as they say, “just calling out for help”.

He refused to take medication after that episode and so the hospital was forced to release him after a few days; there wasn’t much anybody could do. But (What a spoiler!) he hasn’t had an episode in almost ten years. He seems to have done a lot of work on himself, and perhaps the little bit of therapy he’s had, plus conversations with friends, his brothers, and me counts as enough self-therapy.

Back to 1998, things were settled soon enough for Devin and me to make our planned trip to New York, where I’d read at yet another thanatology conference and stay at Roberta’s. There was a small “bonding incident”, as Devin later called it. Something

had happened to upset me (on top of what was already going on with Bret and Jeff); I had left a message on Roberta's daughter's phone at work, would she like to have Devin visit her at work, as she had previously? I reminded her of the fun they'd had last time. She had gotten back to me with, "My dear, you need to not leave such a long message. My boss gets pissed." And no, she didn't have time for Devin that day.

She was right; I did tend to leave long messages. But I certainly hadn't intended to cause trouble. I felt terrible, even after apologizing profusely and being forgiven. And I guess I ACTED terrible for awhile, which upset Dev. "This day's not turning out right," he said. Then he said, for the first time, something which he's said several times in the years following and which continues to be helpful. "Mom, this is the kind of thing to be JUST ANNOYED at." Of course, he was right. But for somebody who has been through, as they say, "more than your share" -- it's difficult to be "just annoyed". "Just annoyed" doesn't quite exist.

That's when the "bonding" started. Of course Dev and I had already bonded, and re-bonded. But when you're a well spouse with a well kid, re-bonding needs to be frequent. One of the things I said was (And this is long, like that phone message.): "Devin, ya know, it would be good for you if someone said the following to you, about me: 'Your mother... well, not only is she wonderful and all that [smirk] but she's had such a hard life, it's really amazing that she does ANYTHING AT ALL. And here she is, taking you to New York.' There is no one to say that, right now. Maybe some day somebody will. But you need to know it right now. And you, too," I added. "You've had a hard life, too. It's amazing what you do, too." Later, over food in a good Chinese-Japanese restaurant,

Dev said, "Oh, I'm having such a good day!" And in the hotel room he exclaimed, "Ooo! What a nice bathroom!" The next day we went to a delicious Mexican restaurant, had cheesecake at the revolving restaurant, then went to the 46th Street Salvation Army. Once again, Dev and I had made it through tough times.

Soon after that I dreamt I was standing at the counter of some computer store; a group of guys stood nearby, talking about spreadsheets or something. One of them -- kind-looking, grey hair, 60-ish -- said to me, "If you'll explain it to me, I'll take you out for dinner." I laughed and shrugged, thinking he was just kidding, but then he said, "WOULD you like to go to dinner with me?" He spoke in a nice, appropriate way. "Yes," I answered. "but there's something I need to talk to you about..." I gestured us away from everybody else. "... well, I have a husband who has multiple sclerosis. He's in a nursing home and... well, you know, I'm married" I gestured just the way I knew I would in real life. This time the guy did not exclaim, "Oh? Which nursing home? How's he doing?" This time the guy said "no, I don't want to get involved in that."

That dream felt good, though; I would not have a dinner date, but I was *sorry* that I wouldn't. I had wanted to go out with that guy. And I realized, upon waking, that I still did. But that wasn't all. In the dream I had had the idea of saying, as I left, "Well, back to work!" or better yet, "Back to Drexel" so if the guy changed his mind he could look me up. In the dream I did have the nerve to say, "Well, back to work" but not the more specific "back to Drexel." I'd been 50% ready. And when I told Freda, who'd been sleeping

over for one of our thrift-a-thon's, she said "Congratulations!" So, that Monday, did my therapist.

That week Normie's husband died. I phoned her around 11:00 that evening. She was busy with funeral arrangements, but she found time to say, "I'll throw you the bouquet." Fern, Rita, Marty, and I went to visit her during shiva. She greeted me, during our big hug, with "I know you envy me." "No, I'm HAPPY for you," I said. "I mean... uh.. I'm SOMETHING for you..." We hugged some more.

There were plenty of other people around, relatives and friends. But "this is the well spouse corner," Normie said, "No one else wants to TALK about it. You're the best visitors I've had so far." She dragged out that word "best". She looked great, smiled and laughed a lot -- from happiness, we felt, not from nervousness. Some of us wondered whether she'd sober up over the months and years, but she didn't.

One day in February 1999 Bret phoned to tell me, "Dad said you were thinking about my moving back in and paying rent."

I had to say, "Bret, Dad gets things all mixed up. Yes, I did talk with him about it -- of course we talk about it; we talk and we care about you. But what I was saying to Dad was that the idea of your moving back in and paying rent was a possibility for the FUTURE." I made sure to elaborate, again, on how well he was doing at being independent, how hard I knew growing up can be, and how I still loved him. Bret seemed to accept that, but later he asked, "Are you planning to sell the house?"

"Well, no, not any time soon. Maybe sometime in the future."

"Dad said he's afraid you're gonna sell the house and move to Florida..."

So then I felt that I had to tell Bret a few more things. “I know this is hard to hear”, I began. “I really do think the M.S. has affected Dad’s MIND, too. Maybe not in physics, but in his judgement. But also, I think that, if I did decide that I wanted to sell the house and move to Florida, I have the right to.” Bret seemed okay about all of that.

A few days later came a phone message from Relli who, remember, had a slight case of M.S. “Hi, Marion. This is a message for Bret. I’m having an exacerbation and I’d like Bret to come and spend the night. I just need little things done like the dishes. Of course, I’d pay him. Can you have him call me back?”

Thinking about it now I almost laugh. Was she *kidding*?! At the time, too, I was concerned about Bret being in a position where he was needed by somebody with M.S. besides his dad. Psychologically it could go either way, I thought. I decided to let Bret listen to the message and he took the job. (Now, I think, I would not have let him listen to the message. Or I would have phoned my therapist first to consult.) But things went uneventfully. It was far from a matter of nights, lifting, and toilet. The next morning I phoned Relli to make sure Bret got up for work. Relli told me that she needed to talk. “I’m scared,” she said, “and I don’t know WHAT I’m scared of...”

“How could she not know what she’s scared of?” I thought. I interrupted her, slowly. “Well, you’re scared of being sick, and paralyzed, and...” Yes, I came down a little hard. But I could not afford any more denial. I’d had it up to there with Jeff’s brand and I recognized Relli’s. I also told her that I didn’t think she should live alone. “I know you don’t like the idea of a retirement community but I think that might be what you need. I’m not the expert on that,” I qualified. “I think you should talk it over with your therapist.”

I had already talked with her like that, but this time I talked even more. I felt she was ready. Certainly I was ready. I also let *her* talk as long as she wanted, and then I said I needed to talk about her condition and how it related to “me, and my family”, in particular Bret. I said that her phone call the previous night had left me feeling concerned, and I told her why. I also said that I thought she had a responsibility to herself, her family, and friends to take care of herself. I said all the things that were too risky to say to Jeff.

Soon I had another Congratulations A+ type dream. I was visiting Jeff and he said something very off-the-wall and I up and reacted. “Look, FORGET it! This is crazy. I’m not gonna come see you any more. That’s it.”

Jeff gave me a look that said, “this is just another one of Marion’s tantrums”. So I said, “I meant that.” I put a calm serious look on my face. And then he believed me. He looked sad, then resigned, then accepting. In fact, still in the dream, he was more accepting than I was. I was beginning to have second thoughts. “What type of video do you want me to get for next visit?” I asked. “Why get a movie if you’re leaving me?” he countered. And yes, I felt sad, scared, and guilty but then I thought, “Yeah, that’s right!”

“I feel like a great weight has been lifted from me,” said Normie. “I’m eating more and in better physical shape.” She was glad not to be going to the nursing home every day and had taken time off from her chaplain and well spouse support group leader jobs. She was having zilch trouble finding new roles for herself. As for me, she had tossed me an emotional bouquet but I was still waiting to be a bride. There I metaphorically stood, holding that bouquet . Everybody was looking at me and clapping. But nothing was happening. Time was going by, and then more time, until the bouquet would wilt and die.

CHAPTER XI: PROGRESS IN '99

My Drexel friend Roberta and I were talking about what we'd want in a man. We fantasized to the fullest. "I'd want somebody who absolutely ADORES me," she said. I could certainly relate. The head nurse on Jeff's floor told me, "if I was in your position and I met someone else that I wanted to spend the rest of my life with, I would." I wanted more of that, from more professionals. But I *needed* it less and less. I began asking myself more pointed questions. "I'm going to be lonely, aren't I? I'll get into the habit of feeling that there's no such thing as not being alone. I'll keep forgetting what I learned through loving, that it's love, symbiotic love, that puts you in touch with your self; it's that type of outer life that makes you feel, extra keenly, your inner life. So, once I don't have love in my outer life, will my inner life go down the tube?"

The answer was also more pointed: attempt to date. Roberta left me a phone message: "I was telling a friend of mine about you and he wants to meet you. He says you're exactly what he'd hope to find in a girlfriend. He's a widower; his wife died of cancer several years ago. He's very nice, one of our very best friends. Would you like to meet him? Maybe we could all go out to dinner sometime."

"I don't particularly want to but I probably will," I told Suzanne. She encouraged me to ad-lib a little so I did. "A widower – ME with a widower? I'd be second choice. And he, of course, would not be a virgin. What could I expect?"

"Tell me more about what runs through your mind," Suzanne said.

“Well, right now, crazy as this might seem, what runs through my mind is: This isn’t fair. I gave birth to babies, and now I have to go through THIS kind of thing again.”

Suzanne nodded. “Yes,” she said. “I know.”

I went on some more about how I felt absolutely no inclination towards sex, or even hand-holding. “And I’m afraid he’ll make moves.”

“But YOU don’t have to,” Suzanne said.

“No, I know I don’t. But I’m afraid that my not wanting to means, or will eventually mean, that I’m cold, or frigid, or something...”

“No, not at all,” said Suzanne. “It means that you’re your own woman.”

One day, picking up the schedule at Curtis Music School, I saw a guy with gorgeous long hair pulled back with a barette; I was talkin’ amazing hair, wavy, abundant, sort-of golden-reddish-brown. And tall, and self-assured. Definitely, I thought, off the charts! “Why CAN’T I have a man like that? I mean. well, I’M like that.” Suzanne and I had been discussing “the peer thing”. I felt a need to connect with my peers. We meant emotional, psychological, social, as well as intellectual peers. People who go ahead and do what they want. People who aren’t depressed or sick. People who dress in stylish black and grey. And men with extremely noteworthy hair! Yes, *physical* peers. There *were* peers, weren’t there? I hoped there were peers.

One weekend in May 1999 I had a helpful revelation. I was recalling a TV program I’d once watched; a woman had had problem pregnancies and after the latest loss somebody suggested, “What about adoption?”

“Oh no!,” she exclaimed. “It wouldn’t be my own. I couldn’t love it the same way.”

Then the person led her into a room where a social worker or somebody was holding a baby. "What about THIS baby?" she asked the woman. Oh, well, THIS baby was different! The woman took "this baby" from the social workers' arms and began to love her, to adopt her. So I, these days. "No I couldn't. We wouldn't be virgins, young-starting-out. He wouldn't be my one and only." But then -- I knew this now -- if someone were to lead me into a room and show me a man... well, THIS man might be different.

On the streets I began to flirt. Not with men but with ideas. I flirted *mischievously*. "Hm, he's cute." "Wonder how old he is." "Wonder whether he's a mathematician." I'd smirk as I flirted. "Is this preliminary or instead of?" I asked Suzanne.

Her answer was "I think it's wonderful."

Mornings I walked in to teach my Calc I class; the male teacher about to walk out seemed nice. Probably too old for me and unavailable. But his smile, and the way it took him a long time to clear off his papers... and he looked a little like the man in my latest man-dream. I even made sure, one day, to come in early enough not to miss him.

I began to thrift differently, look for clothes of less weight and volume, both on top and bottom. I was on the lookout for dating clothes, like what they called a "little dress". Maybe three inches below the knee. But sleeveless, not too high a neckline, and not too loose. Grey, I thought then, dark grey, but not grey that could be mistaken for faded black. I'd wear a "little" black cardigan over it. And heels. Not HIGH heels, but heels. I imagined pre-arranged trysts, love dates in hotels, a honeymoon. I bought two Victoria's Secret short slips. Very naughty, I smirkingly thought. One was black cut-vel-vel. On hot summer nights, I would wear it, alone. "It feels like BONDING," I told Suzanne. "Ya

know, like you do with a new baby. I'm bonding with an ATTITUDE." I was surprised that all that didn't feel nightmarish. I kept waiting for it to, but it didn't.

A few days later I had "the kiss dream". We hesitantly got that far. Our faces were close and he said, softly and slowly, "Kiss...?" For awhile we smiled and shrugged. But then we kissed. Then he pulled away. "Let's stop now," he said. "Let's wait 'til next time."

"Yes," I answered. "That's how I want it, too." Then we just stood there, still smiling and shrugging. When I woke up I called out "Whoa! Whadda dream!" I began describing the dream aloud, to myself. "Kiss. Yes, kiss. I LIKED it. We took it slow."

The next night I had a dream in a different good direction. I was in New York and calling home. Devin answered. "Well, Mom," he said. "Here's the LATEST thing to happen." He paused. "Dad died."

"YES!" I mouthed to myself. Into the phone I said, "How are YOU? Are YOU okay?"

"Uh-huh."

"Do... do you know what happened?"

"Oh, something about he was on the way to the hospital and his blood pressure went 'way up. The ambulance people used all their equipment and everything but it didn't matter. Bret was with him."

"Is BRET all right?" I asked. "Do you know how Bret's doing?"

"He seems fine. He's right here."

"Oh, could you put him on?" So I talked with Bret. Then it turned out Marielle was also there and I talked with her, all the while thinking how I wanted to hurry up and get

home to them, and also how, after that, I would be alone in my room. I could spin around and shout “YES!” to my heart’s content. When I woke up I thought, “Darn.”

One day, at a nearby yard sale, I found myself with Marielle, Arin’s friend Alfonso, and his girlfriend. Everybody except me was young and not single. Everybody was asking everybody else but me what they’d been doing lately. Fonzie and his girlfriend dressed cool. Nobody noticed that I also dressed cool. When we parted Fonzie said “Good luck” to everybody except me; to me he said “it was really nice seeing you again.” I understood how it’s supposed to be with one’s kids’ friends. But I didn’t like it. Maybe I’d have felt differently if I weren’t a well spouse, a well spouse to whom people asked, when I told them about my new job, “How’s JEFF?”

After Fonzie and his girlfriend had left I tried to talk with Marielle about how I felt. “Right or wrong,” I began, “I feel bad and angry right now because it seems -- like I said, right or wrong -- as though no one asks ME what I’M doing.” And then I felt that I had to add, “YOU don’t either -- or at least not today.” We had been talking about how the guy in charge of Drexel’s Honors Program had been very impressed with me, wanted me to teach a course in Math and Literature. Marielle had listened with interest but then there’d been some interruption and when the interruption was over she hadn’t remembered to continue that conversation.

Marielle didn’t understand. She *said* “I don’t understand.” So I tried to stop trying to describe how I felt, but it was too late. I had already spoken. I felt evil. I had felt evil before, or put into the position of seeming evil. Of wishing Jeff would die. Of hurting Jeff, and now Marielle. And then Marielle said, “It seems to me you want ALL the attention.”

Grandeur had indeed been my issue. But that was over ten years ago, in my first round of therapy. My current therapist and I were sure that, to within regressions, I was in control of that. "It seems," Marielle continued, "that you listen to everybody talk, but you're waiting for YOUR turn."

I said nothing, but thought, "Well, the one who hasn't yet had her turn would be the one who WAITS for her turn." But I said only, "I hope not."

For the end of the semester I got the idea of a celebration lunch for the faculty. I put notices in everybody's mailboxes; only Charlie and David could make it. Charlie suggested we try Bistro St. Tropez. And don't think I took it for granted, going out to lunch with (A) two colleagues, and (B) two men. We had a great time. Charlie insisted on paying and then ordered everything interesting on the menu. I liked the way he got all-excited about the food. Then he suggested we look around the Marketplace. It's got all this amazing modern furniture. He was all-excited about it, too; we both kept commenting on the various details. David had left before dessert. I asked myself, "Am I on a date?" And when I got home and told Devin about it, he asked, "Were you on a date?"

Though I'm a modest person and like to keep it that way, I have to be honest about the sex life of this well spouse. I was just as mischevious, fun-loving, and "wonderfully excessive" as Suzanne put it, about what I've seen called "sex for one". I was increasingly gearing up for "sex for two", but not there yet. In the meantime, sex for one was doing nicely! It was, as I told Suzanne, only one of the ways in which I had "a very good relationship with myself".

At Funland playing Skee-ball, I watched the good players and one of them -- a guy -- gave me some pointers and then, tossing me one of the stuffed animals he'd won, said, "This one's for you." He didn't pursue me further, but I had further thoughts. "Am I PASSIONATE?" I later asked Cathy. And to Heidi, "I don't know whether I COULD."

"Oh, Marion", she gushed. "I KNOW you; you're smart, pretty, vivacious, athletic; you'd just naturally move with your body and mind 'cause that's how you are."

I thanked both of these friends. And I had a personal ad fantasy. The guy writes: "Spiffy thrift-shopper with a car, have all day, amateur violinist, love Mozart, hate Liszt, math'n -- I'm working on characterizing associative arithmetics and I've got exactly those lemmas that you don't got. I love babies and I want to hear all about how you gave birth. About sex: I'm mature but a virgin. Never even been kissed. I'm not a writer but I'm a reader. My favorite author is Marion Cohen." It was fun, having fantasies. But I still felt pressured, as though everyone was waiting for me to take the next step, go further than dreams, further than fantasy. Everyone was waiting for news of some kind. True, neither Roberta nor Heidi had come through with their match-making offers, but I still had the feeling that people were rooting for me more than I wanted to be rooted for.

I didn't feel lonely but I felt conscious of being alone. Conscious, these days, of going into a restaurant and answering "yes" when they asked "one?" Conscious of other tables which were not for one. The laughter at those tables, or the business talk, even the silence. Those other tables seemed more prestigious and more fun.

A male Drexel colleague had been interested in my math limericks, and rather friendly. His last phone message to me before the summer had ended, "Well, I'll be around during the summer; perhaps we'll give each other a call; it would be fun to chat."

"Marion!" Freda exclaimed when I told her that. "He MEANS it would be fun to chat. He's definitely interested, I don't know whether in friendship or in something else but he's definitely interested. And by not contacting him you're saying no." So we planned that I'd talk this over with Suzanne and if she agreed I'd email him something like "I plan to come in sometime during August; name a day and perhaps we can have lunch."

Dev had said to me, long ago, "Maybe you should start dating." But on August 17 1999, as he stood in the computer room knowing, somehow, that I was emailing that guy, he said, "It seems like cheating on Dad. I don't know...It seems like maybe you should talk to Dad first and get a divorce."

"Dev," I said. "I know this is hard for a kid to understand; it's hard for ANYBODY to understand. But believe me... well, with chronic illness the rules are different. They just are..." I stumbled for awhile, didn't put it very coherently right away. "Two things: First, I don't want to hurt Dad... He would be SO hurt. Besides, he's probably not going to live much longer and... well, the second thing -- and I know this is complicated but, legally and financially, it would be very silly and cumbersome -- and again, hurtful to Dad -- to go through divorce proceedings, especially since, like I said, Dad's probably not gonna live much longer, anyway. I discussed it with my therapist and she's the one who said it's probably a good idea to just start dating first and see what happens. So it's not only MY idea about all this."

After that, Dev said, “I understand. I really do, Mom. For some reason you keep thinking I don’t understand.” Kids.

Back to the Drexel guy, I felt strangely non-hesitant about that email. On the other hand, I didn’t know how interested I actually was. My druthers were to work on my current math problem. It felt a little like when I had first decided I wanted to be pregnant. Pregnant was what I wanted, not so much the baby just yet.

Two days later there was an email message. “I’ve been trying to work at home as much as possible. I only go in once or twice a week. Is it all right to decide the day before?” It didn’t sound very date-like to me. But still, I thought, friendship with a male colleague wouldn’t be half-bad. “Having lunch with a man,” said Normie, “just feels different from having lunch with a woman. The vibes are different. The ambiance is different.”

“Probably mostly ‘cause of society,” I said.

“For WHATEVER reasons,” said Normie.

I also found out that, when school started in about a month, Charlie and I would both be teaching “Design Math”, the required math course for art majors. Charlie was all-excited about it, wanted to get together and discuss ideas -- over lunch, his treat, he said. Suzanne suspected he was interested in me romantically; I didn’t think so, but wasn’t completely sure. At any rate, he’d be a perfect male friend to “hang” with. I had not had much experience “hanging with guys”, and that would be good practice for dating.

As for the Drexel guy, I soon had occasion to email Freda, “he’s cute, he’s easy to talk with, we had a great lunch -- and he’s married. Some nerve of him!”

One of the aides at Inglis House confided to me some negative things that she'd noticed about Jeff. "I don't like to go in there," she said. "Sometimes I feel sort of afraid." He was needy, demanding, immature, more so than the other M.S. residents. "He drives those kids away, [She meant Arin and Bret.] They order guest trays -- You know, they're growing boys; they're hungry. -- and I'm tellin' you, it happens EVERY TIME -- 'soon as those trays arrive, he suddenly needs to be suctioned. And I KNOW it's gonna happen; I make sure, I go in specially and suction him JUST BEFORE they get their guest trays and still... he drives those kids away. He even drives Alex [That's Lurch.] away... he KNOWS that when you range his legs the way he wants the catheter's gonna come off."

Days later I talked about this with Suzanne. "Here's how I think of it; tell me what you think," I began. "Yes, he KNOWS -- he knows about ALL the inconveniences he causes but, because of the frontal lobe stuff, he doesn't quite make the connection..."

"That's right," answered Suzanne. And more from the Inglis House aide. "He thinks he's entitled to better care than the other residents because of his insurance [which brought in more than Medicaid]. That's how I KNOW he has insurance, because he keeps talking about it." So, I thought, Jeff isn't even politically correct.

I had already decided that, when the time came for me to leave, I'd do it in a therapeutic setting. I'd pay Suzanne double to come with me to Inglis House. I broached the idea to her: "I feel as though breaking up with somebody under these circumstances -- you know, chronic illness, dementia -- is too much to expect a REGULAR person to do. That's something a professional has to get involved in."

Suzanne agreed. "It would have to be set up," she said.

“Right,” I answered. “Like, I’d alert the Inglis House staff to what was going on, and certainly somebody should be with him once I’ve left the room...” Talking and planning like that scared me a little, but then I mentally chanted, “frontal lobe, frontal lobe...”

Indeed there’d been an increase in frontal lobe incidents. Most involved Jeff’s hiring of somebody we’ll call Fred, a nice guy who felt honored to be of help to a physicist. But Jeff kept hiring him for more and more hours, asking me to write more and more checks. I was living on both my Drexel salary and Jeff’s disability, and so was willing to write a reasonable number of checks. But Fred kept phoning to say Jeff owed him money.

I didn’t want to explain to Fred any more than I had to. “I’d rather be involved as little as possible,” I told him. “Obviously, I can’t afford infinite amounts of money. And... well, I don’t know whether you’ll understand or believe what I’m about to say, but keep in mind that it’s something the professionals at Inglis House say, too: Jeff seems to have a subtle kind of dementia. He can, as we know, carry on a conversation, tell the time of day and all that, and he can obviously do physics, but there are various day-to-day things he has trouble with, having to do with interacting with people. And he seems to have a fixation on money, which is common with people in his condition.”

“Yes,” Fred answered. “Jeff seems to be able to do physics but...” Fred was taking me seriously. But I wasn’t naive. I’d seen and been through too much and I knew how attached Jeff’s friends and helpers became to him and his physics. The next time I visited Jeff he asked me to write another check for Fred. “I just mailed it to you,” I said.

“That was last week’s,” he answered. “Now I need this week’s.”

I tried to sort it out. “Oh, well... Jeff, I was hoping Fred had discussed this whole thing with you. He and I had a phone conversation the other day; HE called ME to tell me that you still owed him money, and I told him I had no idea he was owed that much, and I also told him there was only so much I could afford to owe...”

“I DISCUSSED that with you a long time ago,” Jeff interrupted.

“O well,” I thought. Aloud I said, “Fred and I were saying that from now on the money to pay him would come out of your account, as you had said it would.”

“It’s not a checking account,” Jeff answered. “Easy now,” I thought, “frontal lobe.”

“Yes, well, we were saying that Fred could make whatever phone calls needed to be made in order to MAKE it into a checking account.”

“I bring in the paycheck --” Jeff began, and that was as far as I let that go.

“Jeff, I’m not going to discuss it any more. I’m just not. I’m not going to write any more checks and if you say even one more thing about it, I’m going to leave the room.” He opened his mouth and I said, “I’m outa here,” and started to take out the movie I’d put in, adding, “I don’t need to feel UNCOMFORTABLE on visits.”

“I’m not about to say anything about that,” Jeff said. “I want to say something about the movie.” The movie was a very good tear-jerker and it made me feel soft. It also made me feel calm and objective. So I was quite prepared when, after it, Jeff said, “Wait. There’s one thing I want to discuss with you. USUALLY you don’t refuse to talk things over. We USUALLY talk things over with each other..”

”I know,” I answered, still soft and calm. “We’ve always talked things over, usually

again and again, and you usually just don't get it. Or you get it one time and then by the next time you've forgotten, or changed your mind or something. And I'm so tired of that, just so tired... I don't know what it is [I do SO know what it is, I thought. It's frontal lobe.] but I'm tired of it. I don't want to -- I WON'T -- do it any more." He nodded. I smirked. Then I said "bye". I knew he'd gotten it that time but would forget by next time, or the time after that.

That aide from Inglis House confirmed even more. Jeff and Fred weren't really doing physics, she told me; they were putzing around, mostly moving papers from one pile to another. I began talking with that aide about how I was considering not visiting him any more. "In plain language," I said, "if he doesn't die soon, I plan to leave."

"I don't blame you," she answered. "If you leave, he'll be just fine. I'm tellin' you, he's so self-centered, he doesn't notice anything but himself."

She did, though, add that it would be better if I gradually tapered off the visits. Later Suzanne said the same thing. But I wasn't sure. I thought how tense the residual visits could be, how he'd probably spend them arguing with me, asking over and over again, "Why are you doing this, anyway?" I'd have to explain things each time. Sort of like, when a baby wakes in the night and you go to him to reassure him, all that does is remind him of you, and how he wants to get out of the crib. Yes, my tapered-off visits would remind Jeff of me, how angry he was that I wasn't coming around as often, how he'd been "supporting you all these years". Besides, I was impatient to stop visiting; the tapering idea didn't, so to speak, do much for me.

Bret, in the meantime, had been talking with Fred and one day he hit me with “Do you really think Dad’s demented?”

I paused, then gently answered, “Yeah. But by ‘demented’ I don’t mean ‘crazy’ or ‘retarded’ or anything. I mean there are certain AREAS in which Dad’s thinking isn’t clear.”

“Well, in that sense,” Bret answered. “EVERYONE’S demented. Dad’s really smart.” He paused. “Dad and I have been really close.”

My reading on that was: hurt. Hurt about a lot of things. Hurt for a long time. “I’m glad you and Dad are close,” I answered. “I think that’s great.” But then Bret said “I haven’t felt close to you in awhile.” I waited. “Because you listened to the doctors,” he continued. “You believed I was schizophrenic and you wanted me to take drugs.”

“Bret,” I said, once again. “I formed my opinions from a lot of things, not only from what the doctors said, although I did feel good about most of your doctors and I did place a lot of stock in what they said, especially since I know they’ve had so much more experience with these things than I have. But I also went by things that family and friends said, and by my gut feelings.”

I spoke calmly and was not personally upset. Bret had to go through his stuff. Kids always do, not only in difficult situations. I would continue to talk to Bret about all of it, but I would do so patiently. His wounds and youthful misconceptions needed to heal. I would do what I could do. Time would have to do the rest.

Arin, six year older, was better able to process the dementia thing. “There’s SOMETHING wrong,” he said. “I don’t think he remembers certain physics formulas. You know, I told Fred about a month ago, I said to him ‘Ya know, he’s a little bit crazy...’ “

"Oh, THANKS, Arin," I gushed. "I'm really glad you said that. I 'm glad somebody besides me said that."

I wondered what life with a non-frontal lobe man would be like. In October of 1999 I wrote a personal ad. "Vulnerable and Strong: Fun-loving serious poet, author, math prof, 'Jewish agnostic', feminist with a Cinderella complex, 'thoroughly therapied', long brown hair, long black skirts, 56 and everyone says 'No way'. Have been through two of life's hardest odysseys and stayed human and happy. I enjoy thrift shopping, Scrabble, classical piano, movies, ethnic food. Would like to try dancing. Hoping for friendship leading to romance, love, and marriage." I read the ad to Suzanne, she said it was "perfect just as it is", and yes, I should put it in. We talked about fears. The lesser involved not getting any answers. The greater involved getting answers. Perhaps, I said, I'd attract the kind of guy who'd sadistically rub his hands together and think, "Hm, here's somebody really intelligent. Let's see whether I can fool her." Suzanne admitted that that could happen. We discussed it all, and she gave me a list of "red flags".

I talked with Devin about the personals idea and he felt a little "funny" about it. He again brought up the issue of being "unfaithful to Dad", suggesting I get a divorce. Again I explained why I couldn't do it that way and this time he seemed to get it. He wound up saying, "All this would make a great book for you to write". He said it; I didn't!

In mid-November I sent my ad to both Philadelphia Weekly and the City Paper. By the last day of November I had gotten two replies.

CHAPTER XII: THE DIRTY DETAILS YOU'VE BEEN WAITING FOR

You've been very patient! You've gone through almost two books-ful of nights, lifting, toilet, and frontal lobe, and now you're about to get some real love interest!

I, too, had been patient. I had also been, as you've seen, a scared-y cat. Now, though, the first caller was a "senior citizen approaching 70", and he sounded like it. Not for me, I decided. I was 56. For 70, I thought with a chuckle, he'd have to leave a detailed message with the solution to my associative arithmetics problem! As opposed to no details at all. The second guy introduced himself as "Ken", 53 years old, brown hair and eyes, 5'11", non-smoker, "somewhat of a cultural person, like to browse in museums, art galleries... I'm interested in hearing about your various activities, things you like to do... and your being a math professor, that sounds interesting; I have a background in math myself, and that would be something we could talk about... I guess..."

Hm, I thought. Is that "I guess" just-the-right amount of vulnerability or is it a red flag?

"I'm a spontaneous kind of guy," he continued. "I don't like to plan things too much. Let's see... I like, on a weekend --" Oh-uh, I thought. Does he expect me to go on weekends with him?! Nah, probably not, I decided; he meant Saturday OR Sunday, not Saturday AND Sunday! I was having fun thinking playfully; it also calmed my nerves.

Suzanne and I planned Friday December 10 (1999) for our meeting with Jeff. It wouldn't be about any complete separation, just a general discussion around changes that I needed in my life. I also talked to Marielle about how I wanted to "move on" with

respect to “Dad”, including start dating. I told her about the impending meeting. “What kind of things are you planning to talk about?” she asked, and I sensed worry.

“Oh,” I answered, “we’ll talk about the relationship evolving, and my changing mindset. And we’ll talk about visiting every two weeks instead of every week, and how we can make the visits better.” And then, somehow, and probably unwisely, I dared to say, “Right now I feel as though, if I never saw Dad again, I wouldn’t miss him.”

I now realize that was a bit much. I had spoken slowly, gauging her reactions. “You sound COLD about Dad,” she said. “I don’t hear any compassion.” She later added, “I know you do feel compassionate. I just don’t hear it.”

I concluded that I needed to talk more “compassionately” to *Marielle*; she was the one who needed compassion. Now I realize this even more. Still, my real feelings were that, after 22 years, compassionate gets old and trite. Suzanne had a broader view. “Well, I think it’s really hard for adult children when their parents’ marriages break up.”

I also shared with Marielle that well spouses in general seem to come from a different place from everybody else; their compassion takes different forms of expression. “It’s too bad for us,” I said, “when we talk with other people...”

“I guess I just get upset when anybody says anything bad about my Dad,” Marielle said, perceptively and honestly. But who, I thought, is to get upset when somebody says something bad about her *Mom*?

Around then Normie and I had an especially laugh-filled phone conversation. To understand her joke you need to have just a little well-spouse background: As you know, spouses of chronically ill people are called well spouses. And parents of chronically ill

people are called well parents, daughters of chronically ill people well daughters, and so on. So one day Normie phoned me to say, “Guess what?! I was a well DATE!”

“I knew he had diabetes,” she continued, giggling, “but when I saw him limping like that, and his head shaking...” I’m chuckling *now*. Only well spouses, and well spouse sympathizers (like Suzanne), know how to laugh at that kind of thing, though we all know how funny funny-familiar can be.

During the meeting with Jeff and Suzanne, part of me felt compassionate, the way Marielle would have liked. And another part felt the opposite; I simply wanted out and would say anything to get there. Still another part felt the way I sometimes feel when I’m buying a dress full-price. No matter how great the dress is, I’m not absolutely certain about it; I’m afraid I’m being taken in some way; as soon as I take off the price tag, I’ll have regrets. “Are you sure this is what you want?” whispers a little voice.

But yes, I was sure this was what I wanted.

Suzanne began by introducing herself to Jeff, being nice and welcoming, then asking him what his impressions were as to the reasons for the meeting. He didn’t know and I was asked to explain. “Well,” I began, “as you know, I haven’t been happy with the way things are and I’d like to make some changes, in particular in the frequency of visits...”

“It’s sad,” murmured Jeff.

“Yes,” Suzanne acknowledged to Jeff, “it IS sad. You’re right.”

Jeff turned to me. “And later, will you want to visit even LESS often?” he asked.

I’d been preparing for that one. “I’m human,” I answered. Then I lied. “I don’t know.”

In truth I knew perfectly well: I didn’t want to visit him at all.

And then he fell smack back into his old comfort-line. "I've been supporting you all these years." I said nothing. Then he tried "Larry's family visits every day."

"It's his KIDS who visit every day," I answered. "His wife -- as you know, she's a friend of mine from Well Spouse -- is very very stressed out, and she visits twice a week. Anyway, Larry's situation is different; he's new to Inglis House, for one thing. Also, if we're going to compare, most of the residents here don't get visited at all; if they were married, their spouses pulled out a long time ago. At any rate, I don't want to visit once a week any more." That last was spoken softly -- and yes, compassionately.

During the visit I realized that both Suzanne and I were using what I called "the frontal lobe technique", planting things slowly, at intervals. Towards the end of the visit, though, I suddenly and simply said, "Jeff, I'd like, from now on, to visit every two weeks. Is that okay?", and he answered simply "Yes". And now that I'd had some small victories, I found that I felt more compassionate towards Jeff. And it hurt.

I had it all figured out, how to tell my well spouse circumstances to any first date I might have. I wouldn't suddenly hit him with it. I'd lead up to it, thereby also giving other pertinent information, in particular about myself. "I got married when I was 21," I'd begin. "We had two children and then, in 1977, he got diagnosed with multiple sclerosis. (And you know that's chronic progressive and incurable?) Then, of course, his condition worsened. We had two more children (because we wanted to) and later on I did some unbelievable heavy-duty care giving and, six years ago, he was almost completely paralyzed from the neck down and he went to live in a nursing home. And [I'd then pause] he

STILL lives in a nursing home. That is, he's still alive. I'm married. I thought it was only fair to tell you that. For some it would be 'I'm in the middle of a divorce.' For me it's 'I'm in the middle of a DYING.' I also want to say... this might be hard to understand and you might think I sound cold, but... well... I'm over him. I've been ready to move on for a long time. That's how it is with chronic illness: GRIEVING is also chronic. And I guess M.S. lasts longer than grieving. Also: If I fall in love and want to get married, I will DEFINITELY get a divorce. Otherwise not; I don't want to unnecessarily hurt him."

I was sure that was a good way to put it, but I was still pretty scared. And then came a third answer to my ad. And then a fourth, somebody who sounded like Mr. Right! "My expectations are the same as yours," he began. "I spent my early years in New York City [my own favorite city!] and aimed to be a physicist. Intellectually I've moved through physics, math, and now I'm at Penn, as a mathematical psychologist." There was more. He was an "amateur musician, both divorced AND widowed, two grown children, and I have a new little granddaughter that I'm very excited about."

Him I was almost *looking forward* to phoning, barely felt nervous. I answered his voice message with my phone message, asking a few questions: "What instrument do you play? Do you sing? High School of Music and Art? I went to Arts High. You've got a granddaughter? I've got a grandson..." Then I waited for a call back.

It came pretty quickly, and we had about forty minutes of easy conversation. He played not only violin but also piano, and was learning cello. He hadn't attempted the Kreutzer but he played Brahms. And by "mathematical psychologist" he really meant "experimental psychologist". In the middle of our conversation Devin came into the room

to show me his outfit for the day, and David was a very good sport about the interruption. In fact, we kidded around about Gap, Structure, and thrift stores. A little later in the conversation there was another interruption from Dev; he needed to call his friends.

“Well,” said David, “we can continue the conversation another time.”

Huh? I thought. Another *phone* conversation? So I said, “I was thinking lunch.”

“Oh sure, we could do lunch. Sure. That would be fine. I can’t today but... let’s see... how about next Thursday?” So we made a date -- DATE! -- for the following Thursday at Han Wool, my favorite restaurant at the time, Korean. Now I was petrified.

That was the week of Devin’s CAPA audition. That was the only high school he wanted to go to, so I was literally anxious that he get in. At the audition, unexpectedly, they asked the kids to write why they wanted to go there. Devin had time to write only “I’ve been interested in art all my life and...” He’d wanted to say more. However, he did feel that he’d done well on the impromptu drawing of a vase, even though there hadn’t been enough time to shade it. CAPA could take just one in every twenty applicants. I knew that in a couple of months we’d find out; I’d have to go through the harrowing experience of opening an envelope. In the meantime, though, I could concentrate on worrying about my first date in almost forty years.

One worry was that he’d be short. I’m five-foot-nine. Five-foot-eight for the guy would be okay; so would five-foot-seven. But five-foot-six had been Ronnie’s height. Ronnie was my very-first boyfriend. We went out every week for four months, but I wasn’t at all attracted to him and had barely kissed him. Ronnie, although six years older than me, had not had the maturity to realize this. He’d been, I suppose, into denial. So I had to be

the one to break up. I'd been the metaphorical caregiver in that situation, too. Now, aged almost 57, I realized I hadn't put my height in my personal ad. And I was generally scared. But on December 23, 1999, I bravely hopped on the Walnut Street bus towards 36th Street, then walked the block to Han Wool, that Korean restaurant.

"It's not as hard as doing a geometry problem," my mother had said to me forty years ago, about dating. And now I told myself, "it's not as hard as teaching." But it was. I arrived early so got to sit down on their big comfortable sofa and work on that math problem, thinking how impressed, or something, he'd be to find me doing that. And how it might lead into a comfortable conversation. But David also arrived early and he knew it was me. I still remember the moment he walked towards me. And I still feel that same thumping. He had grey hair and he looked old. And short. But he smiled. And we easily killed two-and-a-half hours and, except for no giggling, it felt a lot like having lunch with a new girlfriend. He told me about his work, in particular a very long paper that he was close to finishing. And I did indeed give him my Speil about Jeff, exactly the way I'd planned to. He was sympathetic and wrote down the name of my book.

He had the skill of keeping the conversation focused, and this brought up feelings and issues in me. We'd be talking about me and then I'd think of a question to ask *him*, and he'd say "But we were talking about YOU." At first that felt critical but then I realized something that Suzanne had warned me about: I was so used to being related to as someone who took the lead -- being "parentified", as Suzanne put it -- that it felt strange to be related to as an equal. On the other hand, it was a strangeness that I liked and knew I could get used to.

He talked, he listened, and halfway through our lunch it seemed that his at-first-impression neutral face suddenly turned sensitive-looking and handsome. When we were entirely through with lunch, it seemed even more so. And he wanted to see me again! “Would you feel comfortable coming over to my house to play some music?” Yes, I truly would. I suggested Beethoven’s Second (violin and piano), and he said he’d call me over the next couple of weeks and we’d make plans. It was ostensibly pure friendship, but something big was already in the air.

It was fun reporting this “success” to my friends, but they seemed to be one step ahead of me. I wanted to simply talk and gloat. I didn’t want Freda to say, “And if you wind up sleeping with him, he’s still not the one. You’ll get experience with lots of men and then you’ll know when you’ve met the one.” I knew that wasn’t me. My goal was to sleep only with the one. I’d never in my life slept with anybody who was not the one; I’d be afraid to. In fact, at that point in my life, I was afraid to sleep with the one! I was afraid I’d never be attracted to anybody ever, afraid I’d meet somebody who understood me, and vice versa, but to whom I was just not physically attracted, afraid of meeting a soulmate who was not a body-mate. I was also afraid that by “friendship leading to love and marriage,” David meant only a *couple* of friendship dates. I meant,, well, I’d lived 56 years without him; it would take more than a few dates to get used to living *with* him. I was afraid I was going to be abnormal.

Three weeks later his email moved me. The subject line was “Tomorrow: Music!” The message read. “Hi, Marion. I’m looking forward to tomorrow! The second Beethoven sonata is indeed lovely; I had never looked at it before. I’ve also assembled some other

piano-violin music, to attempt, if you are willing. I hope that you'll have time for supper, as well as music. Either as an intermission (informal, at my house), or after (my house, or a nearby restaurant). And I hope that all is well with you. In case you don't check your email between now and then, I'll phone this evening. -- David"

Something about that subject line, with the exclamation point. Also, "And I hope that all is well with you," the "And". Something very childlike and sweet about it. Almost as though he knew how scared I was. For a minute or so, just now, I hesitated to include that email. After all, why go into such detail? But then I decided that it shows something about David, perhaps the main thing, his essence, before all that other stuff took over. I don't want to spend too many pages on "the David thing", but I do want you to see what I felt about him and, more than that, what a huge happening this was for me under my well spouse circumstances.

That email, plus practicing the music, was beginning to get me in a certain mood. But "tomorrow", just as I was about to leave to go over David's, the phone rang; it was Jeff. Oh no! My mind was spinning. Moreover, he was calling to ask whether Arin had gotten me my birthday present from him yet. It's a notebook, he said, with a pretty cover and blank pages -- "ya know, for your writing". He had that plaintive voice, a voice in the same mood as David's email. Yes, Jeff was a nice guy too. He couldn't help it that he was brain-damaged and ruining my life. I was falling out of love with Jeff and into love with David. In those five minutes I was a bigamist. A nervous bigamist.

But then I was free to go over David's. Once there I felt completely comfortable, not at all sorry I'd accepted his invitation. We had a wonderful time; the Beethoven was "in-

deed lovely” and so was the other music. I stayed ‘til 1:00 AM; neither of us had known it had gotten so late. And, as they say, “nothing happened”, except that we made a date to play music at my house, with dinner on me.

When that day arrived I told Dev that a new friend was coming over to play violin and piano music. “Oh,” Dev asked, “where does she live?”

“It’s a he,” I answered, speaking only a tad significantly.

“Oh,” Dev said, also speaking only a tad significantly.

It’s okay if he thinks it *might* be a date, I thought. We’d already been through that with Charlie, my co-teacher at Drexel. “Where did you meet him?” asked Dev, and I was ready. “Well, he teaches at Penn and I teach at Drexel.” Indeed, that was the truth.

“Oh,” answered Dev. So, I figured, that was that. It occurred to me that I actually *wanted* to talk to my kids about my dating. That surprised me. I had already decided, with Suzanne, that I would not give any details that weren’t necessary. But I wanted to.

Freda had left me a phone message: “I congratulate you and I’m REALLY proud of you. I know that took a tremendous amount of courage -- far more courage than I’VE got. [Pause.] And strength. [Pause.] Yeah,” she finished. That was the Freda whom I knew, loved, and needed. In an actual phone conversation she had said, “And you’re DOING it. You’re doing it, and you’re doing a fine job.” Yes, I had thought, it’s a *job*. Or maybe a *process*. Another odyssey. I didn’t need another odyssey but I’d take it!

I’m modest (in case that’s not clear.) And I realize the position I’m in -- right now, I mean. I feel the way I felt eight years ago, when I wanted so much to talk about the whole thing with my kids but I knew I shouldn’t. So *now* I want so much to talk about the

whole thing with *you*. But I also think of reasons that I shouldn't. First: I know some of you are already against me. You believe I shouldn't have been dating, I was being "unfaithful", about to commit adultery, already doing something wrong. Second: again, I'm modest. I feel hesitant about revealing myself, especially to men, as a sexual being. I think of the things Jeff used to tell me when we were still teenagers, about the attitudes the fraternity guys had towards women, how they talked about them behind their backs. I still can't forget those attitudes that Jeff conveyed. And decades later, during the women's movement of the 70's, my lesbian separatist friend Barbara Ruth had said to me, "I don't want to give strange men pleasure." She meant by looking sexy or "attractive" as she walked down the street. She meant a one-sided pleasure, the kind of pleasure she did not intend to give. I had understood what she meant and had answered, in all sincerity, "Neither do I."

No, neither do I. And I'm afraid that, by talking about my dating and sex life, I'll give the wrong men the wrong kind of pleasure. I don't want any male reader gloating because "the author of *Dirty Details*" or "the math Ph.D." had and has a sex life. In all honesty, silly and childish as that might be, I would rather that men other than Jon not think anything at all about Marion Cohen's sex life.

Yes, I'm modest. But if I'm to tell the rest of my well spouse story, I've got to spill at least some of the "dirty details" (the ones you've been waiting for!). A well spouse's sex life is, as things evolve, a huge part of the well spouse story. Not only the longing for sex but the fear of sex, after being away from it for so long, having unwillingly put on catheters and done toilet, being raped in that way. I need you to know how I hesitate to tell

you that, after two dates with David (and I wasn't even sure we were considering them dates), something on my end was hot. I would, for awhile, continue to not want the actual him, but I did want the fantasized him. And, I hesitate to say, I fantasized to the tune of many orgasms, without touching literally a hair of myself. Soon I began feeling the hormones. Suzanne later told me it was oxytocin. And indeed, it was like what I'd felt during the first few weeks of the Devin-pregnancy. There was a physical tingling through my arms, torso and legs. I felt it most of the time. Sometimes as I was teaching I thought, with an inside giggle, "You-kids think YOU'VE got hormones!"

But second dates always did get me nervous. That's when the guy maybe makes a move, when he sort of has a right to make a move; the girl's already indicated that she likes him, by accepting this second date. So she sort of doesn't have as much right to say no, or that was the feeling I had. "Lighten up," said my sister and I tried to. Everyone kept reminding me that I didn't have to do anything I didn't want to. My sister said, "I know this has been said before, but nothing is a matter of should." Still, I felt that I *should* be wanting to have sex, *should* be moving further along in some way, *should* be in second-date mode. In a sense, I was in care giving mode. What was I supposed to do? Well, one thing I decided was, not only was something hot, something was warm.

On the second date, though, "nothing happened" except that David said, upon departing, "I had a great time, an even greater time than I usually have when I get together with people and play music." Also, I looked at him and thought, "He's not THAT short. He's full-sized, human- sized. Yeah, his height is of the same ORDER as mine." I also realized that, although he stood shorter than me, he stood taller than a person in a

wheelchair. There were stars in my eyes after he left and the next time I visited Jeff and he asked me to pull up his testicles... well, it felt even more not right, even more like rape. "I'm dating DAVID now," I thought.

"Do you feel that there's anything wrong with wanting to be just friends for a while?" asked Suzanne.

"Well, yeah, sometimes," I answered. "I Like, here I am, 57 and afraid of sex, wanting to not have it yet. What am I, some kind of baby?"

"No," said Suzanne. "I think it's lovely and sweet." Yes, something lovely, sweet, and precious was going on, albeit hot. It felt a little like labor. Hard work was being done. I was in a rite of passage. Being human, being a woman, is hard work. Suzanne liked the way I "struggled", the way I lived "the examined life". So did I. An examined life is a *double* life. You get two for the price of one. "I think I'll keep me this way," I thought. Suzanne put her hand on my arm and said, "Oh, I'm so happy for you, Marion."

When the time came for me to phone CAPA, the high school of Dev's choice, there was a half-minute pause before I was told that Devin was on the accepted list. Thank Goodness! Moreover, David called that morning to ask whether Dev had gotten in.

Valentine's Day had come and gone. On that day first the wrong man, the one who used to be the right man, had called to say Happy Valentine's Day and then the right man had done the same thing. But that had been all. It was too early for the romantic Valentine's Day dinner I had been fantasizing about. But most of my friends said things

like “You deserve this happiness. It’s about time.” And I thought how unfair it would seem if “this happiness” turned out to be more sadness, more pain, more horror that I didn’t yet know about. “Oh, I hope,” I said to Suzanne, “I hope he’s the type to just ADORE me, and to be adored, and to... oh, always be in touch with me, even when other people are around, to not only hold my hand but squeeze or pat it, to be WITH me at... well, most times, and to be romantic.”

Suzanne answered, “I hope so, too.”

But was David was thinking of me “that way”. Perhaps he was merely excited to have me as a friend and accompanist. Looking back now, I almost laugh at my doubts. *Of course* he felt “that way”. He asked me to dinner and to the movies, played me a set of Lieder about love and longing. And finally, one evening at the movies I suddenly felt ready. I looked at his hand and wanted it close. So I moved my own hand just a little closer. And then, just as suddenly, his hand was on mine. I turned to him and said, quietly, “yes”, and took his other hand. Then we watched the movie, clasping, patting, rubbing hands. Soon my head rested on his shoulder.

Every once in a while I looked at him. I thought about how he wasn’t Jeff. And how that seemed okay. More than okay. It *shouldn’t* be Jeff. I didn’t WANT it to be Jeff. I wanted it to be David. Yes, this was very right.

And then, life-examiner that I am, my mind filled with questions. What will happen next? What will he expect? What do I expect? Does this mean he loves me or is only attracted to me? Then I thought, just wait’ll I tell Cathy! Wait’ll I tell Freda!

After the movie we quietly walked outside. "I was afraid you didn't think of me that way," I said. "Well, I do," he answered. But then in the car he started talking about the movie. I said, "I wasn't concentrating that much on the movie. I was thinking of... well, of you." He didn't answer. Yes, the path of true love -- or of false love, as it later became -- never runs smoothly. There's awkwardness. Suzanne later clued me in to that. The awkwardness, she pointed out, is part of the loveliness.

We then went over my house, as planned, and ate the dinner I had cooked. We talked about how we were beginning a relationship. I told him I was scared and he seemed to know I meant scared about sex. I reminded him how long it had been. We talked seriously for awhile. I told him about Jeff's brain damage and he said, "It sounds like you maybe NEVER had a relationship with a man, and your feelings about me could wind up being very complicated."

I answered, "Oh, I think I'll be just fine." "Let's go play some music," I said after a while, and we did -- with that slight difference. After a while, though, I began to worry how the evening would end. I knew I wasn't ready for sex, maybe not even kissing. But I needn't have worried. David ended the evening just right. He gave me a caress -- I still remember it; it was a BIG caress, passionate, comforting, and long. I dared run my fingers through his silky hair and kiss his cheek. Then he pulled away and looked at me; I thought he might be debating whether to kiss me, and was relieved that he didn't.

"I'm happy," I said. He answered, "I'm happy, too."

After he left I sat down at the kitchen table, touched my face with my hands, in utter disbelief. "Oh my God!" I exclaimed. "Oh my, my! Did that really happen? I'm not dreaming, am I? Oh my God!" At 1:45 A.M. I whirled through the house singing Brahms.

When a person who's been blind has an operation enabling her to see... well, at first she *doesn't* see. See is an active verb. Her eyes need to get used to the action. And so I needed time to allow myself to take David's hand, snuggle up, phone him whenever I felt like it. This formerly blind person... well, the light hurt her eyes. Shapes were blurred, or sharp. Objects were moving too fast. Some objects were too large.

David understood this and possibly felt the same way. And so things proceeded, as Suzanne kept assuring me, perfectly fine. During most of 2000 I had, not only a relationship with David, but a romance. Of course I got over my fear of sex (with the help of some friends and "How to Make Love to a Man"). David said those three little words and so did I. We said them quite often. And if I weren't so modest, I would tell you more -- beautiful things, things I'm proud of. It was literally like music. In fact, through David I was attaining a better understanding of music -- poetic things, like how maybe the violin is *supposed* to sound a little scratchy; we're supposed to feel that friction. And that it's okay for the violin and piano to not be exactly together; that's part of the urgency.

"Marion, you do realize how amazing this is, don't you?" said Freda. "And do you realize it's a tribute to YOU, how amazing YOU are. Enjoy it. You deserve it. Marion, I remember you handling bedpans." Yes, I was aware of all that and yes, I relished hearing Freda say it. And much as Freda appreciated what was happening, much as she felt

the difference between my life now and my life just two short months ago, I felt it more. I also felt the fear, the fear of a switcheroo.

But those moments of fear weren't often. Mostly I basked in what was going on at the time, things he said to me. "You're lovely." "You're unique." "You feel so good." "This is a miracle." "You get more and more beautiful each time I see you." Quite a far cry from "Mar. Toilet.", "Mar. Suction tube."

David and I walked around the neighborhood a lot, holding hands, so I knew I'd better tell my kids before they found out in some other way. That was something I was sort of secretly looking forward to, but I also had my apprehensions. Marielle was sensitive about her Dad, and Arin and Bret were in some ways obsessed with him, the classic same-sex association with a parent. I planned how I'd do it. I'd take each aside individually and say, "I have something to tell you, something I'm very happy about, although I know you'll probably have more complicated feelings. Remember, I told you several months ago I was thinking about dating; I wanted to try to find love and happiness again. Well, I've been extremely lucky and I've been seeing someone." I'd be gentle. Instead of "the most fantastic guy", I'd say "someone who makes me happy". I'd continue, "We're taking things very slowly but we like each other a lot. I know that might bring some turmoil to you, with Dad and all, but I also hope you'll remember that I lifted Dad and washed bedpans and got up thirty times a night, and that Dad couldn't think of a way that I wouldn't have to do those things, and I hope you see that Dad can't give me what I need right now, in terms of love or even companionship."

I was encouraged by Suzanne, and by my sister who said “Basically, kids are happy when their parents are happy.” Marielle hugged me and said, “well, of course, you know it’s a little hard for me. But I’m really so happy for you.” Arin and Bret each shrugged and talked about “marriage vows”. I just listened as they expressed their feelings. After awhile they all met David -- at a special dinner, at Family Night, at birthday parties, and so on. “He feels like one of the family,” Marielle soon told me. “But I don’t get a sense of the two of you as a COUPLE.”

Indeed, David had turned out to be shy and repressed about acting like a couple, first with respect to “affection in public” and later with respect to affection in private. He turned out to not be quite what Suzanne and I had hoped he would be. What Marielle had said was a harbinger, and it got to be more so.

CHAPTER XIII: MORE HARBINGER

Jeff didn't go away. I visited him every two weeks. Of course, I didn't tell him about David, nor did I say, in Suzanne's words, "the marriage is over". When is he gonna die already?, I wondered once again. And then I couldn't help myself; "Well, it's HIS choice," I quipped to Normie (rest her soul). "If he dies soon, he doesn't have to find out about David. But if he continues to be this un-wise, he might get 'punished' by finding out.". As a former well spouse, she was also seeing someone seriously. If I were less modest, I'd tell you some of the "dirty jokes" that we created (okay, I'll share the one about multiple sclerosis (M.S.) vs. multiple orgasms (M.O.) -- ya hadda be there.). "It's so great that we can share this," she said. "You know, it feels so good to be a woman again."

When I visited Jeff, I didn't feel guilty at all. In fact, in a strange sense, those visits were helpful. The obvious contrast between the way Jeff treated me and the way David treated me clarified matters for me. Still, visiting Jeff was feeling more and more weird. I tried to think of things to talk about, but by then everything about me involved David in some way. I was careful to talk about teaching and the kids. I had Kafkaesque fears that, in the midst of a visit, Jeff would suddenly blurt out, in an angry and half-sadistic tone, "So? How was your fuck with David last night?" That would feel scary.

Writing all this, I think again about how readers will react. Most, I know, will be cool and caring, like essentially all the people I've come across. But there will be some who'll say sarcastically something like "Poor baby!", the way women sometimes say about men who feel guilty about the women they literally fuck over. To those who say or think

things like that, I wonder what I could answer. “I WAS a poor baby,” I could say. And if that’s not clear by now, I probably can’t make it clear at this point. But I’d try. I’d say that, not only didn’t I hurt Jeff, but I helped David. Meaning, I made not only me happy but him. As now I’m making Jon happy. I truly do wish I could convince everybody. Often simply *informing* is convincing, but not always. I wish it were.

“One thing I’m worried about,” David said, one day in March 2000. I bent over, placed my face near his, let him know how intently I was looking at him. “Yes?”, I asked.

“Well, you know how you say that, when we play music, you don’t hear it when I’m out of tune; you hear what you want to hear. Well, I’m afraid maybe you do that with ME. Maybe you’re making ME into what you want, what you expect.”

That was another harbinger. More and more things were feeding into his insecurities. Eventually it translated into self-centeredness. I certainly didn’t need more of that.

“The only important thing is the way I feel about you.” He said that in March of 2000. By the end of the year, though, he was saying, “Did I really say that?” I certainly didn’t need another guy who didn’t remember things about us.

Towards our beginning he said, “I find I’m so nice to people these days. It’s because I’m happy.” I must have wondered, in some ‘way-back burner, “Are you usually NOT nice to people? Are you usually NOT happy?” I certainly didn’t need another guy who was usually not happy or nice to people.

When David first read “Dirty Details”, he phoned to tell me, “It’s quite moving, very

well written, and really unique.” I wondered, “Is he also going to say how sorry he is that this happened to me?’ No. His thoughts took another direction. “Of course, there are parts of it I don’t WANT to read. Like when you ask, what happens to love when...”. I understood what he was getting at. He was worried what I would do if *he* got chronically ill. I assured him but it didn’t seem to help. A little later on in that phone conversation, I said, “I feel like wrapping my arms around you and comforting you.” And now I’m thinking, huh? He should have been the one saying that to me.

In bed one night David had a cramp and I began massaging it. Massaging him really turned me on. But he said, “I don’t want to remind you of Jeff.” I said words to assure him that he wasn’t and in general I was eloquent in reassuring him of things. That eventually became more and more necessary, and more and more difficult to do.

And when was it that he began to be even busier? Sometime late-spring, perhaps. First it was the paper. But then it was what I termed “post-paper”. Like post-polio, only immediately. “Nope, not tonight, either,” reads my diary entry of May 10, 2000.

That was the first wave of feeling as though he were putting “us” on hold. “I don’t know what I can do,” he would say. “I’m rushing as fast as I can.” I didn’t need another person to be putting me second, sort of pleading with me.

At our beginning he had told me, “You’re teaching me a lot about feelings.” But a teacher needs a learner and he soon seemed to be getting tired of learning; a teacher gets tired of teaching a learner who’s tired of learning. Besides, that’s not what it was supposed to be about. I didn’t need another guy who didn’t know what it was about.

“I’ve called you a few times” said Jeff, “and you’re not there -- where ARE you?” In truth the answer was usually “upstairs in Devin’s room, not hearing the phone”. But I felt very upset and scared.

On Mothers Day I wanted David to pick me up from visiting Jeff and take me out for a Mothers’ Day dinner. But David said, “Actually, I don’t feel comfortable going to Inglis House.” “I don’t blame you,” I said. But we could have met a block away. In general, there was a brand of soft and warm that seemed missing. The stars in my eyes were beginning to fade. I didn’t need another person to put out the stars in my eyes.

On another occasion David said, “Strange, but when I realize I say things that hurt you, I still don’t stop.” I didn’t need another person who couldn’t stop hurting me.

I had been longing for further wonderful things. More courting, or the end of courtship and the beginning of marriage or move-in. I realized it had been only five months, but correct timing in a relationship is an individual thing. For this relationship, so it seemed to me, his timing was all wrong. Something seemed stuck. And the wonderful things he couldn’t sustain. But, except for a few hints and attempts, I kept mum, for now.

When I said “You work six days a week...?” he answered, “well, I’m a scientist.” Indeed, so was I, as well as a writer. Also, he didn’t pet my cats.

Were these regular relationship problems? Or impossibilities, like with Jeff? At first Suzanne assured me it was the former. “Okay,” I thought. “I know what to do. Just keep making him feel comfortable, and accepted.” But then I reflected that that’s what I’d been doing all along. Also, it could translate into “Just keep being good. Then nothing can possibly be your fault.” And that, of course, would lead to more time passing, more

variables arising. I'd eventually break down and tell him what I was feeling. I'd keep on telling him; I would talk too much. I didn't need another loved one to talk about "Marion's temper tantrums".

A heel like Jeff? Socially-underdeveloped like Jeff? Passive aggressive like Jeff? Maybe. But certainly not brain-damaged. No, that couldn't be. Please, no.

Around this time I was diagnosed with trigeminal neuralgia. "It's rarer than M.S.," said my doctor. An inflammation of a facial nerve, it can feel like a toothache or jawache, and be excruciating and unresponsive to medication; surgery is risky. It comes and goes during the day or night. So far I had a rather mild case, and over the course of several weeks we found that it responded completely to neuronton. Suzanne said it might be a case of stress; "GOOD stress is still stress," she said. Besides, by then there was a fair amount of *bad* stress.

On the bus with David to New York, before we had worked out the medication, I had some very bad pain. "I'll feel better if you hold my hand," I said. And you're not gonna believe what David said; "I'd be happy to. Unfortunately, I first have to fold the newspaper." He took his time with that, and in fact first continued reading. The pain eventually stopped. But I didn't need another guy for whom my pain wasn't a priority. I should have broken up with him right then and there.

Still, Normie and I continued to talk, giggle, and be happy together. "Sometimes," said Normie, "all Morris has to do is SAY something and..."

“You’re KIDDING?!” I exclaimed. “Me too!” We were like teenagers, going nuts. “That’s ALL I wanna think about,” I continued. “When I look at him, that’s what I think about. He talks about his work or some article he read and all I can think about is ---”

“Me, too”! shrieked Normie. “So I’m NOT crazy after all! Morris talks about his business or something and I hafta work really hard to pay attention.”

“I know. Sometimes I feel so stupid...”

“Oh, Marion, you’re not stupid. You wrote all those books and you have a Ph.D....”

“HOWEVER did I get it?!” I shrieked. “I guess I wasn’t thinking about THIS at the time.” We went into hysterics.

Later Devin said he’d heard us from the fourth floor, two flights up. I was horrified. “Not ALL of it! Devin, you didn’t LISTEN, did you?”

“Well, I heard you say ‘orgasms’ -- Sorry, but it was so LOUD.” Oh well, I thought.

Arin and Bret told me that “Dad” sometimes said to them, “What kind of wife only visits her husband once every two weeks?” -- “What kind of wife has M.O.’s with somebody else?” I mimicked to Normie that evening, laughing loudly though feeling a trifle scared and newly shocked by it all. Very slowly and quietly Normie answered, “A very wonderful loving person, that’s what kind.” “Thanks, Normie,” I said.

Suzanne gave a lot of thought to the question whether or not I should tell Jeff about David. “This way,” she said, “this whole Jeff-thing wouldn’t be at the center of everything; there wouldn’t be this big secret. It might free everybody up, maybe even David.”

One night I actually asked David what *he* thought. He had some interesting takes on it, but delivered far too dispassionately for my taste. And although I'd prepared myself for his not taking that opportunity to ask me to marry him, I still felt hurt that he didn't.

Decades ago when Jeff first told me he loved me, I asked, after things had sort of settled down, "Do you mean marry me and everything?" The answer was "yes". Forty years later, I didn't quite understand these new rules. To me love meant forever. What was David waiting to find out? Whether I kept being smart and interesting? Whether I kept being pretty and sexy? What was it that I had to keep being?

Increasingly there were things he was worried about. Pain in his left elbow, memory loss, the fact that the publishers of his paper hadn't emailed him back about something he'd emailed them about. He didn't seem to be worried about anything concerning *me*. And I certainly didn't need another guy who worried about everything except me.

He knew that his behavior had much to be desired. Once I said to him, "I love you so much. I love you so much," and he answered, "I don't deserve it."

"What?!" I exclaimed.

"Well, I'm often... oh, not so nice..."

"Yes, true," I answered. "But I see through you; I see YOU. But the fact that you don't deserve it, or whatever... I hope that doesn't mean you won't TAKE it."

He smiled, said "no" in a nice voice and kissed me. That kind of thing probably bought him a few more months with me -- until he reached the point where he would not "take it". That was another thing I didn't need.

No matter how many evenings I was willing to forgo seeing him, he always added at least one to that number. Sometimes he'd say he couldn't see me that evening because of paper revisions, then he would *not* spend the evening that way but on something else, thus giving him the same reason to not spend the next evening with me. Suzanne said that his "nasty behavior" (as he called it) was a depression symptom. The indecisiveness, the anxiety. "Talk with your psychiatrist," I began to ask, almost beg him, "and bring me." In August I said to Suzanne, "I have a feeling there's going to be another tragedy in my life."

"Not necessarily," she answered. "Probably not." She didn't say "DEFINITELY not".

Still, none of that affected the lovemaking, on either the physical or the emotional level. Each time felt like the first, the first with him and the first ever. He had observed that, too. He continued to use words like "amazing", "fantastic", "miracle", but less often. And things were better during August. He seemed to be trying very hard to be "attentive", as he put it, and to not be "nasty". He said wonderful things, like "I've never felt this way about ANYBODY", spoken very slowly. His birthday happened to fall on the same day as Jeff's. "But I'm not superstitious in that way," I had told him when I first found out. In fact, I kind of enjoyed that situation. It made for a fair amount of humor.

Jeff's birthday celebration was the doing of the kids. We had cards, presents, and a cake which he couldn't eat. And David's celebration was the happy doing of me. As is my custom, I bore many gifts. The one he loved most was my collection of poems to him. I called the collection, "Poems to Make You Blush (Both Red and Pink)". The next evening I got a phone message. "Best birthday ever! Those poems are WONDERFUL.

You are amazing. [Pause, deep soft male voice.] I love you.” I saved that message for the full 30 days. He had plans to vacation for ten days with a friend, in the mountains, so I wouldn’t see him during that time. He phoned me twice. “I’m thinking about you -- a lot.” When he got back he was thrilled to see me. He was a happy and loving man.

But then he told me that he had decided, without consulting his doctor, to go off his depression medicine completely, and suddenly. “And I’m feeling perfectly fine,” he said. I knew that would not last. And so I wasn’t surprised that, within a few days, he began acting more and more distant, less and less loving. When I asked what the problem was he’d say, “I’m worried about, after the paper’s done, what next.” He began to work *seven* days a week. “I already HAD my vacation,” he said. “Now I have to work.” To say “he drove himself” would be an understatement. Jeff’s M.S. might have been a result of driving himself. I didn’t need a repeat of that.

“I’m surprised at myself,” he said. “I really did think I wanted marriage and commitment. I don’t really understand what’s going on with me.” I didn’t need another guy who didn’t understand what was going on with him.

He had suggested that, instead of talking about any of the big-M’s, we make a commitment to not break up, to “keep things just as they are”. That didn’t seem very romantic to me; in fact, it seemed sad. I realize that works for some people, but not me. To my mind he was simply resisting the flow. And then, to my mind, he didn’t even feel the flow. By November he seemed to have ceased loving me, most of the time. Suzanne assured me it was the depression. He had gone back on the medication but it would take time to kick in, six weeks or more; I should not try to argue him into or out of any-

thing during that time; it would do no good. Just, of course, like trying to argue Jeff into or out of anything. I certainly didn't need to be arguing with brain dysfunction again.

Now I think I should have told him that the depression was causing him to be too "nasty", even abusive; I could not allow myself to be subjected to that. When his act was more together, I should have said, I'd see him again. In the meantime, I could have added, I'd miss him very much. I probably would have done that very thing, eventually, as I eventually insisted Jeff live in the nursing home, and as I eventually started dating -- maybe I was too "eventual" in those years. As it was, I continued to be very very patient, not allowing myself to be abused but also not confronting him very much. When we made love it was still wonderful but he seemed to be avoiding that. I knew the depression medicine could be the cause. In fact, he had pointed out, it could make one not have desire either. Another thing I didn't need, somebody to not desire me.

And then he insulted *Kerin*. My dead baby. Whereas he had been just lovely concerning her at our very beginnings, now when I gave him a copy of the new edition of "She Was Born She Died", his first comment was "I found three typos."

At one point I couldn't help asking him, "Are we still lovers? Do you still love me?"

"Oh, Marion, that's ridiculous," he answered, too quickly. But I had to factor in the depression. "Something is wrong," said Suzanne. "It seems like he loves you, and he's right for you, but he's holding back." She added, though, "I really do have a feeling things will work out." It kept me up at night. I was "vulnerable and strong", as my ad had said, and right then "vulnerable" was at the forefront. "Strong" would be used later.

Through all this I asked Jeff for a divorce. As I write that now, it seems abrupt, and also not a very wise thing for me to have done -- especially after the fact, and facts, of what followed (though it all probably would have followed anyway). I knew that, divorce or no divorce, as long as Jeff was alive, I would be embroiled in his illness, and financial crap. Still, the thought of being free of the marriage seemed like fresh air.

Again I asked Suzanne if she would go with me when I confronted Jeff, as she had a year before when I talked with him about visiting less often. Again, it would be less stressful for me and since Jeff wasn't perfect cognitively, it was important, not only to have somebody else there besides me who *was* perfect cognitively, but also if Jeff said anything harmful or nonsensical, there would be a witness. And when it was over, I might be feeling tormented, confused, even sad, and Suzanne would be available for me, for the next hour. She would have experienced every moment of it, unlike any friend I would phone to talk it all over with.

She and I set a date, and I phoned Jeff to tell him there was something I needed to talk over with him, my therapist would be there also, and was that date okay with him? I was worried it wouldn't be. And then I was worried something would come up like his J-tube coming out or another bout of pneumonia. But none of that happened.

Our marriage had run 36 years. We had enjoyed shopping together for Oriental rugs; we had both liked them asymmetric. He had been present at our bridal shower, at a time when it was unheard of for men to be, and he had also been present at Kerin's baby shower. And we had grieved really well together, none of that business of having different styles of grieving. And all those trips to Europe, London, Florida, hotels like the

Fountainbleu, all paid for by NASA or NSF. When Bret was a baby, we had lingoed together. You know how babies cry and you finally figure out what it is they're crying about. As Bret was handed the correct toy, or as he ate on me, I would lingo, "Is THAT what you wanted?" and Jeff would lingo back, "Yu-up. That's would 'e wanted." Jeff had wanted every pregnancy, attended every birth. And never fail, if I put my fingers to his lips, he'd kiss them. (And it felt weird when David didn't.)

During those last few days I re-read my adolescent diary. I had described meeting Jeff on that bus riding home from our respective schools. I had spent the evening with him at a Y dance but he hadn't asked me out, not 'til a year and a half later. Then it had taken awhile -- far longer than David and me -- to really get going. The diary ended the day after we had sex. My first ever. I ended the diary because I felt that I now had somebody to confide in, I didn't need a diary. Re-reading that entire diary, I went back in time, not loving him again but remembering loving him. I knew I needed to do that; it was a step towards closure. Reading the diary and not falling back in love with him, not falling out of love with David, was a good sign. I realized that I had, indeed, loved two men. I felt lucky to have been in love twice. Another thing I did in preparation was to take the huge 3 feet by 4 painting of Jeff from the living room to the third floor hallway, where it still hangs, just yards from where I am now. That was symbolic of the fact that I did not intend to ever forget Jeff, but I also did not want him to be the first thing that people (including David) saw when they walked into my house.

So the day and the hour came. Feeling strangely un-nervous, I did everything according to plan. "As you know," I began, "I've been rather concerned about my own life,

where it's going, where it should go, to what extent I want to or should continue to devote my life to you. And as you also know, I haven't been very happy lately. I need and want love, and I want to go on with my life. I've been 'doing this' for a long time and I've reached a point where I don't want to any more. I do want to keep visiting and be in contact with Inglis House to make sure you're well taken care of, but it can't be the main thing in my life. Also, you're so involved with your own struggles that you can't really be there for me, you can't be all that interested in me, can't really love me." I paused, then said quietly, "The marriage is over." I paused longer and, kind of shrugging, as though I didn't quite believe it, said, "I want a divorce."

Jeff quietly took it all in. He didn't ask why, didn't try to talk me out of it. He seemed sad, was quiet a lot but not all of the time. His voice, as described earlier and throughout most of this book, had been weakening. He agreed that we would be "amicable". He wanted me to keep visiting and he seemed to feel that we were good friends. "Buddies," he said. "Well, we STARTED OUT being buddies in the first place." A little later he lamented that there was nobody else with whom he felt very buddy-like. "Really?" I said. "What about Fred? What about the rabbi? What about ..."

He stopped me. "They're not YOU," he said. That was very moving and I was very moved. I assured him, again, that I would keep visiting him. Afterwards Suzanne said, again and again, "You did amazingly well. Both of you. I don't think I've EVER seen a couple communicate as well as the two of you did. I was very impressed and very moved. I can't imagine it any better."

Only two things had been weird. First, Jeff, true to form, wanted us to save money and do the divorce ourselves. I was already familiar with Jeff's do-it-yourself schemes and was not about to agree to a do-it-yourself divorce. The second thing was actually creepy. Direct quote: "I can't eat any more so I experience eating vicariously by watching cooking programs on TV. Maybe you can tell me about how things are with you and your boyfriend so I can experience romance vicariously?" I'm reminded of the film, "Breaking the Waves", in which a demented man tells his loving and loyal wife to go out and have all kinds of sex with all kinds of men, then visit him and tell him about it. She winds up getting killed by those men.

The next day was the Inglis House Fair and I visited Jeff again. "Do you feel maybe a little less tense, now that I've told you what I've really been thinking?" He merely shrugged. "Well, I feel less tense," I said. Then I told him how Suzanne had complimented us, and to what extent. I hoped that made him feel better in some way. Devin had told me that Dad seemed sadder than usual; he even thought he saw a tear in the corner of his eye. I hoped it had been only a small tear.

David's paper was *chronic*; even once finished, it never went away. It provided a progressive, exacerbating excuse not to see me. And when he did, he was distancing. For the 2000 presidential election, for example: our voting sites were different, even though we lived three blocks from each other. "Too bad we can't vote together," I said.

He answered, "I don't think of voting as a social activity." No, he was not a safe place. And I certainly didn't need another unsafe place.

It got worse and worse. It felt scary, cold, lonely, and drab. It felt like grieving time. Suzanne had said to me, at the beginning of the romance, "Oh, you'll have your various relationship problems. But nothing like Jeff. David doesn't have frontal lobe stuff." But now we both acknowledged that he, too, had *some* kind of stuff.

It got still worse. He found an excuse (namely, the post-paper) not to come with me to the Messiah sing-a-long. Things were such that I wasn't in the mood for making the annual carolling party so I skipped it that year. December in general felt pretty grim. One night I dreamt that David had telekenesis and was using it to try to kill me. The connection that I made was, telekenesis equals distancing. He was killing me with distancing.

On my birthday, January 2, he took me out to a nice restaurant but acted more as though we were just friends, brought me home at 9:00, saying he had work to do. By that time I was not protesting very much. The following Monday, as we had decided, I went with him to his shrink. I had planned to tell that shrink that I was concerned; David's depression seemed to be very bad and it was affecting the way he was treating me. I had planned to ask the shrink whether he felt it was the depression or that he no longer loved me. I also planned to ask whether he felt I should continue seeing David. I had hoped that something wonderful would begin to be accomplished.

Here's what happened; it shouldn't happen to a nazi, I thought at the time, let alone a well spouse. I was telling the shrink, "We have no trouble expressing our love for each other. We say 'I love you' a lot. But not lately. And," -- I turned towards David; he sat to my left on the couch -- "well, I still love you; do you still love me?"

Happy and secure with Jon, I still freeze as I get ready to write this. David said, simply and compassionately, “My feelings have changed.”

I turned to ice. “You mean...,” I gasped. “you mean, you don’t love me any more?”:

“I don’t know,” David answered. “I just don’t feel what I used to feel. It’s not anything you did; I just don’t feel that way any more.”

I stayed ice. “You mean, all this time you haven’t loved me. And I’ve been sleeping with you... you know it’s not like me to sleep with somebody who doesn’t love me. And I asked you, I ASKED you whether you still loved me, and you said that was ridiculous.”

At one point the shrink had the nerve to say, “Well, you SAW how he was acting...”

“Uh, actually,” I began, tears in my eyes but feeling very focused and articulate, “I certainly did see how he was acting. In fact, I MENTIONED to him how he was acting, asking whether he still loved me, and he said ‘Of course I do. Don’t be silly.’ I wasn’t very satisfied with that, but my own therapist reminded me that he’d gone off his depression medicine and wouldn’t be the same until it kicked back in. She advised me to ‘give it another month’. Besides, David also said things like ‘It’s that I’m pre-occupied with my work’ and ‘I get very shy at times. And having very strong feelings doesn’t prevent the shyness; in fact, sometimes the more strongly I feel, the shyer I get.’ ”

His shrink sort of retreated, or that was and is my impression. “Oh,” he said.

That was the shrink appointment from hell. But I held my own. “Oh, so he doesn’t love me”, I said measuredly. “So now I understand”, all the while crying but quite poised. We ended the session by agreeing to talk some more, but I planned to talk first with Suzanne; I had the feeling that I would decide not to see David’s shrink again.

The car ride back was rather strange. Probably David felt more embarrassed than I did. I felt simply heartbroken. Dropping me off at my house, David took my hand. I wasn't interested, not under those circumstances. He said he didn't understand what was going on with him, or how he felt about me, and he also said he would go to Suzanne with me and he'd like to continue playing music with me, I was "really such a good friend". I said I probably did not want to do that.

Suzanne advised me to take him up on his offer to join me in our sessions. It would provide closure, she said, and possibly she could bring him to his senses and he'd love me again. Also, the depression medicine would be kicking in some more. Of course she understood what I was going through but she felt optimistic. She also told me repeatedly, and I needed to hear it repeatedly, that it was not my behavior, nor my issues. that had caused David to behave the way he did. My issues -- in particular, being a well spouse -- would plug into the way I *felt* about David's behavior, make it hurt more than it would have, resemble stuff with Jeff, and so on. But they had not *caused* anything.

Like most people growing up in the 50's, or during any period, I'd been given the impression that when a relationship is in trouble, the trouble is caused by both parties. "It's never any one person's fault," I'd been told. But anyone who has dated, in particular anyone who's had relationship after relationship, knows that's not true; one person can be, not "at fault", but with issues or habits pervasive enough to preclude any reasonable long-term relationship or commitment to anybody at all. Put another way: sometimes a relationship is as strong as its weakest link. I had learned all that. But I still had that 50's mindset, at least a little. Or rather, I worried that other people would have that mindset,

that they'd think I must have been half-responsible for the failure of David's and my relationship. Suzanne made it clear that I was not *at all* responsible.

For two months David went weekly with me to see Suzanne, except when he was busy (which was rather often). In our sessions David was often caught saying unreasonable things. One stands out: I was lamenting how hard this was on me, already stressed and sad to the gills. David's response was "I feel as though you're saying I was deliberately taking your heart along for a ride."

"No," I said, "I know you weren't deliberately taking my heart along for a ride. But I do think you were NON-deliberately taking my heart along for a ride." David was silent.

As time moved along he began to express his worry about the "logistics" of our (former) relationship, not only Jeff but also the four kids. "I've never met a woman with a situation so complicated," he said. That made me furious. First, he had known about my situation early on. Secondly, he didn't seem to feel bad for *me*, being in a "situation so complicated". Thirdly, was I doomed by this situation to never ever be sustainedly loved by a man? Was I doomed in general? I was determined not to be, and I said all these things to David, ending with "if you, or anybody else I love, were in a difficult situation, I would do anything in my power to stand behind that person." Again David said nothing.

During this period I still loved and longed for him. Sometimes what hurt most was, I loved him so much that I felt sorry for him; he wasn't taking the love that I believed he needed Deep Down Inside. I wished I could stop him from hurting himself.

We saw each other only at Suzanne's. She had, of course, been right in suggesting we have these appointments. She was able to confirm many of the speculations I'd

made about David, so I got a lot of closure. I also harbored some hope, especially when Suzanne said, "I can see he gets pleasure from being with you" and "I can see why the two of you were together". Still, I didn't need to be at these weekly often degrading meetings in which somebody was deciding whether or not he loved me. And indeed Suzanne said to me, "I really don't need to see you any more. I see where YOU are; I see that the problem is HIM." So she began seeing David by himself; I joined them only once in a while, for 'consultation'.

At one point I told Suzanne, "I want Jeff to die but I will not cause his death. I will not pull the plug." I made sure to write that in my diary because besides worrying about so many other things I worried that, when Jeff finally did die, I would be blamed, and charged, maybe executed. Well, they'd say, she had a motive. I was very careful to not be alone in Jeff's room with his door closed.

In my Drexel classes we still had fun. One Vector Analysis student kept answering all the questions and I finally said, "someone else this time." That smart student, though, knew the answer again and couldn't resist. He spoke in a voice obviously higher-pitched than his usual, pretending to be some other student, and we all laughed heartily.

Suzanne was encouraging about David. "Don't give up on him. He has a BIG problem with self-image. I've worked with couples in similar situations, even worse, and... well, I have a good track record." But I felt that my life had broken a few track records. Later she said, "I have a feeling -- I'm not positive but I have a feeling -- that he's maybe beginning to love you just a little bit more, maybe beginning to come around."

Perhaps defensively but also savvily I replied, “Just watch. Next week he’ll back-track.” “You might be right,” Suzanne answered. “He IS the kind who, ’soon as he begins to make progress, gets cold feet.”

I had taken steps towards practicing meeting other men. I continued to have lunches with Charlie and developed a friendship with Joe, who’d joined the faculty that year. We shared our life tragedies. (Both his parent had died unexpectedly during his senior year in college.) And walking along Market Street one day, I had my eyes peeled and this guy held my gaze. “Hi,” he said rather pleasantly. I kept the eye-contact. “Good morning,” I answered. After a pause he said, “You ARE looking very nice this morning.”

Indeed I knew that I was. I had on a long grey jumper over a flattering white top, but what showed was this \$5 long navy coat and slightly-different-from-most black beret. It was all from thrift stores. *He* looked nice, too. Smiley and tall. If it weren’t for David, I would have told him as much. Instead I just said “thanks.” We both sort of shrugged. I felt that we might have gotten along. He could have been anything from trash collector to college professor; I would never know. I still sometimes wonder.

The next day was one of our threesome therapy sessions. David began, “I’m wondering whether we should continue with these sessions. I don’t think I’ll ever get to feeling the way I felt last March.” I had indeed been correct in my conjecture to Suzanne.

“Marion,” said Suzanne, “this is probably really hard for you. Do you have anything you’d like to say right now?”

“No, not really,” I answered, already beginning to move on. “I think I’ve said enough. I think I’ve already said and done everything I could to show David where I stand and

how I feel. Suzanne, can you think of anything I've talked about with you that's significantly different from what I've said before in these sessions with David?'

"No," Suzanne answered. "Neither can I," I said. A few minutes later I did say a few things -- with dignity, I felt. "I don't know why my life doesn't want to be good. I don't know... but I do know that I'm going to get through this. I know that I'm not going to give up. I also know that, through this whole thing, I haven't done anything to be ashamed of. And I'm satisfied with the way I'm handling things RIGHT NOW."

David soon excused himself, leaving Suzanne and me about fifteen minutes to sort things out, and to cushion whatever blow I was feeling. I asked her whether she had anything scheduled for that next hour; she didn't so we took that hour. "You do know that I'm not crazy, don't you?" I asked her.

"Absolutely," she answered. "You're just responding to too much grief and too many injustices." Indeed. The next day, going through my "important papers", I came upon something which began to worry me sick. It was a statement I had written and signed many years ago, when Jeff first went to live at Inglis House. "I promise that if Jeffrey Cohen gets better he can come back home to live at 2203 Spruce Street."

I'd written it mostly because I'd been vaguely afraid that if I didn't, he wouldn't agree to live at Inglis House. In other words, I wrote it under duress, something many well spouses do. Much later a lawyer told me that paper wasn't legally binding. It was neither dated, notarized, nor witnessed. But at the time I thought "How could I have been so stupid to not realize I might want to move or divorce?" I phoned Suzanne and she said, "Yes, you do have to get out of your relationship with Jeff."

“Society has to help me,” I answered. “SOMEBODY has to help me. I’ve already helped myself plenty. I know ‘God helps those who help themselves’, but that’s not fair. Sometimes those who don’t help themselves can’t POSSIBLY help themselves, because they’re tied up or something. I’ve done plenty to help myself and it doesn’t work. Somebody has to do these things for me. I can’t, any more.” I threw up my hands.

Still, by and large, here’s where I stood: The way, minutes after finding out that my baby Kerin was dead, I began talking with Jeff about having another baby -- that’s the way I felt immediately after finding out that David was dead to me. That evening my friend Kim told me about love@aol. It’s free to aol users and I got on right away. I “met” two men and began emailing. I also put up my own profile. As long as I was emailing some guy, hope was in the air. Just like, post-Kerin, as long as I had ovulated and was possibly pregnant, I didn’t feel horrible. Hope springs eternal. In my adolescent diary I had once written, “Damn hope”.

I didn’t cry at first but eventually I did. I had plenty to cry about, more than you think.

THE BAD YEAR

One day at the bank I saw that Jeff's disability check hadn't been deposited. I immediately phoned him. "Oh" he said, "you can live on Devin's social security."

No we couldn't. Nor would it be legal to. That money was specifically meant for Devin, in particular for his college education. Matter-of-factly I told Jeff all this, knowing it would do no good. I was not panicked -- I was teaching full-time -- but I knew Devin and I would need that money, and we had a right to it. Jeff was being taken care of; he did not need it. He only imagined that he did.

I phoned Jeff's helper and got nowhere. Then I immediately called my divorce lawyer. Yes, this was the beginning of what I called "the bad year". It actually lasted almost two years. Many things, not only my love and financial life, went wrong. I didn't believe in destiny, not in "magic" or God, yet it seemed that happenings were suspicious. I announced that at a poetry reading; the "theme" of my reading was "a bad year". How does an individual's bad year relate to the world's bad year? How should an individual react to a suspiciously bad year? I read poems with lines like "O, Law of Averages! Why hast thou forsaken me?" My audience was attentive and responsive. "And what," somebody asked, with a half-wink, "if you had a suspiciously GOOD year?" We all laughed but I answered seriously, "I would still be suspicious. I would still not like it."

During the same week as David's chilling revelation in his shrink's office, one of Normie's sons died, of a disease they had not expected him to die of. Next, that summer I got a very bad email from the chairperson at Drexel; the subject line was "Next year". I

knew immediately what that email contained. I had lost my Drexel mathprof position. Things were being changed around; they were now concentrating on computer science, engineering, and business. Not pure math. That day I emailed all the local colleges I knew of and by that evening had an adjunct position at Widener. In a few days I had an offer from Arcadia and possibly Swarthmore. I wanted only two courses, and the schedules all conflicted anyway, so I took only Widener.

Okay, so at least I got jobs. Enough to live on, along with partial Unemployment plus the monthly payments that the lawyer was eventually able to get from Jeff. Over the next couple of years University of the Sciences wanted to hire me full time but the funding for that job fell through. Widener wanted to give me a full time auxiliary position but the rules there preclude Ph.D.'s getting non-tenure-track positions. There were other promising developments that never came through.

Several good things *almost* happened, just as David had almost happened. "It's better to have loved and lost than never to have loved at all" – and I loved, or began to, and lost again. Three months after the breakup, I met a guy at one of the Viewpoints Math/Art conferences. At first things seemed perfect. I could imagine a movie about it. It would begin as it actually happened, with the introductory meeting of the conference; we all sat around a huge table. In walked two latecomers, and about one of them I thought, "Wow!" His hair was in a ponytail and his face was handsome. Also, he was tall, maybe six foot two. "Wow!" I thought. "Who's HE?! Could I possibly get HIM?!"

We all introduced ourselves, saying whatever we wanted others to know. He mentioned that he was interested in trying to get students to actually *see* math, and I

thought, "Hm. I just got lucky!" For I'd recently read about Keith Devlin's book "Making the Invisible Visible". I called out my info. He wrote it down. "Maybe I COULD get him," I smirked to myself. At dessert that night I got bold. Although we hadn't started out at the same table, I moved to the empty chair on his left. He turned around, clearly happy to see me. He was soon enamored with me, especially once he heard me read math poetry and give a short lecture on "tiling the plane with regular polygons: the rest of the story". (I considered the idea of polygons tiling the plane N -fold, not only once.) He repeatedly said, "I really enjoy your company". I was enjoying his company too. Our personalities were similar. We became "conference buddies". He too was married, in the midst of a divorce. And on the second day he let his ponytail down to reveal hair the length of mine. By then, too, he had ordered my books from Amazon.

The conference was three days long; we had most of our meals together. I would have liked it if he had actually asked me on a date, but he didn't. He did, though, want to exchange email addresses. He lived (and lives) far away, on the other side of the country, and he hated his town but didn't want to leave his well paying job. Very shortly after I returned home from the conference he emailed me. "It would be my sincere pleasure to help you get your poetry website up and running. Just email me any poems you like...." I was quite happy with this respite from "the year". And I hated it when friends said, "it's impossible; he lives too far". Lifting something heavier than you off the floor and onto the toilet is impossible. Getting him off the toilet when, every time you wipe him (and you had to), it "stimulated" him to go more -- that's impossible. Convincing a demented spouse not to hurt and harm you is impossible. Moving to CA, or PA, is not impossible.

Not very far into our frequent email correspondence he told me, “Just so you know: I believe I could very easily develop romantic feelings towards you.” I was enthusiastic in my response. “I was WONDERING when you were gonna say that.” But he didn’t say much romantic after that, nor did he move forward in any other way. He seemed to agree with my friends. I had the kids, if not Jeff, here in Phila., he had nothing where he was, except that well-paying mathprof job. Perhaps it was naive of me to think like that, but perhaps not. He continued to be very complimentary of me, eventually emailing, “You’re very close to my ideal woman.”

But I was not looking for the type of person who would continue to live in a town he hated. Or who would continue to not give serious thought (or not that he shared with me) as to, having finally met somebody who was truly right for him, what he might do about it. I felt that, like David, he was running away, from himself as well as from me. We emailed as friends for quite a while and then it petered out.

That was the best anything got during the bad year. Nothing ever went anywhere. I was jumping out of my skin. The third very good thing that almost happened during that “bad year” involved another book. At the Viewpoints math/art conferences, one of the participants who’d published a book about “groupwork” in college classrooms was so enamored with my “math poems” that she asked whether she could communicate them to her publisher. Of course I said yes and soon sent a book-length manuscript. It went all the way to the final meeting, and then I got her email. At first glance I thought it said “I have good news...” Then I realized it said, “I’m afraid I do not have good news...”

These things happen. But they happened more frequently during that bad year. I did get a math paper into a British teaching journal, help form the Well Spouse Divorce/ Separation email list, write many “bad year poems”, get most of them published, give successful poetry readings, and make several new friends who helped me tremendously through that period. But anything really wonderful seemed to refuse to happen. I tried very hard to force it to. I did not try *too* hard, as some might say. I simply refused to accept that this state of affairs was forever. I spent hours at the computer with love@aol and other dating sites, and advertised in newspaper personals. I was driven to find a man to love. “Do the things you like to do, anyway,” I was advised, in particular by myself, but that didn’t have much effect. Concerts, film discussion group, Philadelphia Ethical Society, just sitting in the Square... it seemed men no longer were interested in women. If they were, it seemed they didn’t ask women out. Sometimes I’d get into great conversations with guys but then they’d just say, “Well, I’ll see you.”

I was not a very good loser. I wanted to turn my life around, even though it didn’t seem to want to be turned around. Freda, however, felt that I was a great loser. “You sound very strong and centered,” she emailed, “not happy but together and a Mensch. Congratulations. One doesn’t always like the cards dealt but there is real grace and elegance in how you are playing them.” And yes, I felt and feel she was right.

My first poetry reading after the David break-up was significant to me. After reading some non-David poems I said, “Now, some of you know I’ve been in a difficult situation involving the chronic illness of my husband -- and how chronic that situation has been. Well, last year I surprised myself by falling in love again. [Pause] That was the last

thing in the world I thought I'd do. I never thought I could..." Then I read "My First Dream of You", "Brahms", and others, ending with "Tonight". I did not read anything erotic; I didn't want any man in the audience to talk about me afterwards in *those* ways. Then I paused again, a little longer this time. "And now it gets sad. It... it didn't work out." I read "love-disappointment poems", ending with "Conversation with the Mirror", in which my reflection and I unite in determination to not be discouraged or ashamed. I had fantasized that, afterwards, some cool guy might come up and say something like "Yes, I've been there too". And indeed, a man did just that, but he wasn't for me and I knew it.

Every once in a while Jeff had been asking, "Do you have a boyfriend?" I had lied but added that I was still rather young and would be for a little while longer. During that visit we watched a movie. The movie was romantic and ended happily, and just as I was about to leave, Jeff said, "And WE seem to be making progress, too."

Inwardly I gasped; outwardly I shrugged. Silently I moaned "please". On my way out I decided to sit down on the steps and let myself cry out aloud, though softly, "please let him die." I realized that what I wanted was to talk with somebody. And -- my lucky day -- suddenly I saw Delores, my favorite aide right at the top of the stairs. I knew that, if she wasn't busy, she would gladly spare me a few minutes. I also knew that those few minutes would help. "I need to talk with somebody," I said. "Do you have time?"

"Of course," she answered. She came over and put an arm around me. Then she steered us into the lounge. "What is it? HIM?" she asked, gesturing towards Jeff's room.

"Well, yes," I answered, "him, too. But also the new guy, that you know about. He turned out to have big problems, and in general it's just been so LONG...."

But then “BRRING! BRRING!” Fire drill. Delores had to go close doors. She urged me to wait for her. “I’m so sorry,” she said. She did return, but only to say she had still more doors to close, I could wait and she’d return. But I saw bad handwriting on the wall. “Thanks,” I said. “But I think I’ll just go catch the bus. It’s getting late.”

Alone at the bus stop I talked to myself. “I KNOW things like that fire drill just happen, it’s not a Sign or anything. It’s not the powers that be telling me I’ll never have even a moment of somebody Coming Through For Me.” That past week Cathy, in the midst of sympathetic listening, had suddenly gotten a long-distance phone call, Freda’s mother-in-law had suddenly walked into the house, and something had even happened with my therapist. “No,” I said aloud. “It sure the shit ain’t the time for the law of averages.”

Home that evening, Dev upstairs, I heard the phone ring. Delores calling to check on me, see whether I was okay? No, Jeff’s helper Fred. He needed to come over to pick up some of Jeff’s books and papers. When he arrived he was mostly on his own but every once in a while he bothered me with some question or other. Is he strong enough to rape me? I wondered. True, he wasn’t strong enough to lift Jeff, whereas I was, but that didn’t necessarily mean he wasn’t strong enough to lift, or to rape, me. Well, thought the quirky bitter mathematician in me, it’s not my time for the law of averages; why should it be my time for any transitive law?

I’d been thinking about selling my house. Four huge floors, just Devin and me, I could have something nice and modern that didn’t need fixing up. Our house had been a bargain to begin with; I could sell it for many times what we’d paid. Also, it would be something positive, to have some control over, and for Devin to get excited about. But

Jeff, though he hadn't been in the house since entering Inglis House, was unwilling to let it go. "I thought if you didn't get a divorce, you'd keep the house," he told me. For indeed, I had decided to not get a divorce. What would be the point?

"Huh?" I said quickly. "Why should you think that? Anyway, we've been through all this before. Devin and I both don't want to live here any more and that's that." And that was indeed that, until a few minutes later. "When you buy a new house, will there be a room in there for ME when I get better?"

"Huh?" I snapped. "What? I mean, yes, there will be an extra room in there but... but I'm not thinking of things that way. I mean... Gads! You're driving me crazy!"

And so he was. Yes, sometimes I snapped. Usually I didn't. As I was leaving that day, he asked, "So you're not planning to divorce me?"

Again I snapped, or my nerves did. "No, I'm not. I don't want to talk about it any more. Stop it! It's driving me crazy." And again, so it was.

During another visit Jeff said to me, "I called up Social Security and they said you took \$14,000 from me."

"Huh?" I answered. "Jeff, this is OUR money. I'm sure I used whatever money you're talking about for household expenses. And where did the \$14,000 come from?"

I tried to get Inglis House to prevent Jeff from inflicting further financial abuse. I told everybody. I told them long, and I told them well. "I neither can," I said, "nor should handle this alone. Professionals need to step in. I've reached the point where I feel I absolutely cannot continue and still keep sane and healthy. Eight years ago I was being awakened by Jeff thirty times a night. And I told the professionals THEN -- I TOLD them

-- and nobody said I didn't need to be doing this, Jeff should be in a nursing home. I had to figure that out for myself, I had to initiate things; it's in the last chapter of my book. So now -- same thing. Jeff has dementia, we all know that; he's doing things that hurt me and my children, and the system is looking the other way. No one is doing anything, or acknowledging to me that they can't do anything. The system is failing me again."

I wasn't finished. "I'm asking for help. You can't say I haven't asked... I'm really sorry to have to be saying this -- HAVE to. Time is of the essence. If possible, he needs to be stopped before he does further damage."

Yes, I did report it. I also literally begged them to give him another "psych eval"; he hadn't had one in years. The psychiatrist agreed. I also requested a meeting with a social worker; she, Jeff, and I would try to work things out. But the meeting mostly smacked of "couples therapy", and Jeff reiterated and added to his financial intentions: Not only did he plan to pay me (and Devin) monthly amounts only on a temporary basis -- three months, he said -- not only did he not plan to pay me anything retroactive (meaning five additional monthly payments), not only, after the three months, did he plan to give me only what the law demanded (less than a thousand a month, in 2001), not only did he not intend to take on his share in the cost of Bret's insurance (which he needed in case of another psychotic episode), not only did he intend to not let me sell the house, and not only would he want half of the money if the house sold, but I owed him \$42,000 -- I had STOLEN \$42,000 from him, he insisted. (Yes, \$42,000, rather than \$14,000 as he'd said before)

The social worker had been rather cool about that one. "Let's get this straight. You think Marion stole \$42,000 from you." "Yes."

I had been even cooler, or hotter, depending on your viewpoint. "Jeff," I said. "That's terrible. That's abusive. And that's it. I won't be abused. I've been through 'way too much for that, I couldn't take it and I don't deserve it. So I'm not going to visit you any more. It would be horribly degrading to be visiting somebody who accuses me of stealing money, who feels that way about me."

I meant that and I kept meaning that. From then on I visited him only when he was in the hospital. That did help. At the time, though, I felt very alone in protecting myself; not much protection was coming from this social worker. After the meeting she brought Jeff back upstairs to his room and had me wait in her office. I thought when she returned she'd offer words of comfort or affirmation, perhaps even insinuate that during the meeting she'd only been humoring Jeff. But when she returned she said only, "well, okay...." (like "u-huh") I was feeling too exhaust-ed and too down to be assertive in any way. I let her say "you and he don't communicate" and "the two of you don't agree". I did not answer, "How can ANYBODY communicate with brain damage. You couldn't communicate with him, either" or "How can I agree that I owe him \$42,000? How could I meet him even halfway? What am I supposed to do -- agree that I owe him \$21,000?!" Instead, that time, I felt and acted the way oppressed people sometimes do.

Soon afterwards I discovered that the psychiatrist, who'd promised to let me know when the day of the psych-eval would be, didn't. One day he simply informed me that Jeff had been diagnosed as competent. I was furious but not surprised. Psych-evals did

not test things like whether he believed I had stolen money from him. I understood that their hands were tied. But I didn't, and don't, understand why they were so evasive with me, sometimes insulting. I didn't understand why they didn't level with me, why they continued with this new version of the conspiracy of silence. They seemed to be *pretending* to give him a psych eval, pretending to try to intervene in his financial shenanigans. They seemed to be holding onto some secret.

One phone call to Inglis House stands out. It was with somebody who had in the past been extremely friendly and nice to me, but in this particular conversation she pulled what seemed to me a complete switcheroo. Her voice sounded tired, or tired *of me*. As though I'd been phoning her all the time, whereas in reality I hadn't in months. I was talking with her about the financial stuff Jeff had pulled, trying once again to see whether Inglis House might somehow do something, or at least try to. "I'd advise you to contact a lawyer," she said. "That's the professional to contact."

I reminded her that I already had a lawyer, which of course I was paying for, also that somebody else on the Inglis House staff had suggested I phone her. But she didn't seem to hear me. "I don't mean to sound unsympathetic," she said.

"Well, you DO sound unsympathetic," I answered.

At one point she said, "You're welcome to phone me at any time -- about nursing matters." That had never been her tune before. Before I had been "welcome to phone" her about *any* matters; she had told me that specifically.

I ended the conversation. "Okay, you've answered my question. Thank you -- bye." Then I phoned the director of Inglis House to complain, telling him that she was usually

very cordial and friendly to me but had spoken rudely in that particular instance; I gave details. A few days later he phoned to tell me that he had reprimanded her and insisted she apologize to me. A few days after that I received a phone message from her. "I'm sorry if I said anything to hurt you." Nothing else, in particular nothing indicating that she knew what she was apologizing for. To them all I felt like saying, and actually did at various points, "It's not that I AM a problem. It's that I HAVE a problem."

"That's right," said Suzanne about that.

I left a phone message for the director saying I had not been satisfied with the apology. I didn't expect the director to call back and he didn't. Then, perhaps too persistently (but I was feeling very persistent in those days) I phoned him again. This time I reached his secretary; she apologized for not getting back to me, saying she'd passed it on to her boss, adding that she'd felt that I (and others like me) don't want to hear back from *her*, but from someone higher up. "Thanks!" she laughed, meaning "thanks for wanting to hear from me." Eventually I told her, "When you, or Person X, doesn't call back, it feels to me as though Person X feels as though I'm being a pest or out of line."

"I see," she replied, "and all this time I was thinking... well, I'm learning..." This same person later told me that she'd read "Dirty Details" thoroughly and was "learning" from it, learning the ways in which people in her job engaged in "the conspiracy of silence". That encounter was heartening, but it didn't improve my situation.

The psychiatrist asked me to write up documentation of Jeff's "alleged" dementia. I did just that and got back from him an email. "I am sorry to have to tell you this but I have very carefully reviewed all the information you sent and past observations of your

husband, and I find nothing that could confirm a condition of legal incompetence to manage his affairs. All the material you sent and at my disposal could possibly indicate a psychotic condition -- but it could with at least equal plausibility support the notion of a vindictive and self-centered, but non-psychotic, and fully competent, husband. I understand and am sympathetic to your plight but must advise you that you will need to pursue other avenues than the psychiatric, at least for now.”

I noted that phrase, “legal incompetence”. My guess was, psychology had evolved to the point where it had tests to distinguish between psychotic/ incompetent and vindictive/ self-centered, but the legal system had not evolved to the point where such tests were used for anything remotely pragmatic. The system could prove incompetence but not do anything about it. At this moment I’m reminded of DNA tests to prove somebody’s innocence of a crime; I’ve heard true stories about purposeful delay in running such tests, people festering on Death Row for years waiting for the red tape to unravel.

Perhaps those in charge at the nursing home were as frustrated as I was -- perhaps more so, because of the sheer number of cases like mine. Perhaps they needed to be in denial of such stupidity and injustice, and of their own powerlessness. Perhaps that’s why they kept so mum, why they were incapable of communicating effectively and comfortably with me. I do still wonder. I wrote the psychiatrist another letter, in which I told him some of my feelings. I did this for the same reason I had told the director’s secretary how it felt when he hadn’t gotten back to me, and indeed for the same reason I wrote “Dirty Details” and this book -- because I want the people in charge to know, and maybe do something about it, for somebody if not me.

In my letter I said that judging Jeff competent felt to me like judging *me* incompetent. It was, I said, a lot like the situation in a rape trial: A verdict of not-guilty for the rapist entails a (non-legal) verdict of guilty for the rape victim. It judges her guilty for being stupid, mistaken, too sexy, "asking for it", etc. The implication also is that she wasn't raped. (The death penalty abolitionist and prisoner sympathizer in me was quick to add that all that I didn't believe rapists should be executed or even punished; what I meant was, the crime to the victim should be *acknowledged*, the *victim* should be acknowledged; to me it's not a matter of punishing the criminal but of compensating the victim. In that same spirit I was not asking that Jeff be punished or have all his rights and privileges taken away -- only those rights which impinged on the rights of his family.) I said that I felt little or no acknowledgement, compassion, or respect from those in charge. Judging Jeff competent felt to me tantamount to believing the things he said about me, the things that had gotten back to me via the aides and sometimes via my kids -- things like I was a spendthrift and, again, I stole his money. It all felt very much like "blaming the victim". The whole scenario, I continued, felt like "cruel and unusual punishment", for me, the victim and upright citizen. Devoted and loyal wife, mother, teacher, author, caregiver; I had committed no crime -- why was I being dealt cruel and unusual punishment? I felt that Inglis House, which had in the past been extremely supportive, seemed to suddenly be shutting down that support. I said that my therapist would verify that I was not paranoid, that it indeed seemed as though there were some secret being kept from me or as though certain interests were being protected. It seemed puzzling and upsetting to her too. In the letter I reminded the psychiatrist that many professionals, including some at

Inglis House, had read “Dirty Details” and assured me they would do everything they could to break that “conspiracy of silence”, but that in many ways they did not. I also asked, “Are you all really less interested in protecting your patient’s family than in so-called protecting your either demented or very cruel patient”?

I didn’t say the following in the letter but I thought, and asked Suzanne and some of my friends, “Are they all really THAT stupid? Do they really think they have to be ‘impartial’ and the only way to be ‘impartial’ is to pretend Jeff is competent? Do they really think that’s what ‘protecting the patient’ means? Do they really think protecting the patient means neglecting to protect the patient’s family?” I couldn’t believe that anybody, in particular anybody professional, could be that stupid. “But who knows?” I then thought. “Maybe it’s like nationalism. ‘My patient, right or wrong’.” Unconditional love, or unconditional protection, isn’t supposed to include letting the person do harm to others. But I guessed, in astonishment, that maybe those in charge thought it was. Moreover, how could they forget about his family when I was so often reminding them? I concluded that it wasn’t forgetting they were doing, though I wasn’t quite sure what it was.

Something else occurred to me and I still wonder: ‘way before all this happened, when Jeff was in the early M.S. stages but it was clear that the progression was not going to be slow enough to let us “ride into” old age and death... well, the professionals must have known what could happen? They must have known his dementia was very likely to lead to the ruining of his family’s lives? Why, when he was in better mental shape, good enough to reason and to care about me and Devin more than he cared about money, why were we not warned and counseled? The M.S. progression couldn’t

have been prevented, but this harrowing side effect could have? Why was it not? Why, in a society which has developed such elaborate psychological tests, is there such lack of imagination as to what can actually be done to curtail harm to families? Why are society and “those in charge” so behind in this?

Indeed, I had many good ideas, some of which I expressed to those in charge. Sometimes I was given lip service, sometimes only a nod and an “u-huh”. I understand now that nobody except my lawyer had the power to help my family, but why such nods and “u-huh’s”? After Jeff died, I realized that society did indeed do some things to help, but only after I had *already* been going through the mill. The very existence of nursing homes and of lawyers, the powerless support of most of the people at Inglis House, Social Security for Devin which now more than pays for his college, Social Security for me once Jeff died, plus Jeff’s pension which did, despite my worries, get willed to me and the kids. I realize that indeed we were compensated to some extent for all we had gone through -- but very late in the game. Not at the time when we really needed it. And, for those well spouses whose ill spouses don’t die, never rather than late.

Online I met wacko after wacko. I spent hour upon hour with love@aol, but “Lonely guy” turned out to be a practicing Catholic, and “Are you lonely?” turned out to want women under 40. None of them said anything much about music or math. Nobody asked or answered questions. Most wrote like third-graders. More than one promised “winning and dinning”. And just as I used to fear second dates more than the first, I often discovered that what seemed like “pink flags” on the first email quickly revealed them-

selves, on the second email, to be bright red. One guy who wrote “you sound too good to be true” in the first email wrote about sexy food images in the next. (But I had fun forwarding these wacko emails to friends, especially Normie.) One guy seemed interesting and interested; an artist, he emailed me some of his work and asked me to send some of my poems. Then out of the blue he emailed, “Hey, I have an idea. How about you write about how you would feel if you were to pose for me?” With another guy we made it to the lunch stage. We had an acceptable time and made plans for another date. But then, during the week, he emailed me a question, “If someone is an exotic dancer, would that be okay?” Another promising guy bristled at “friendship first”, from my profile. “But friendship, lovemaking, passion -- they all go together,” he said, at the very beginning of our first (and only) phone conversation. “Huh?” I said. Inside I thought of logical answers, not necessarily for his ears. “Friendship doesn’t require as much trust as lovemaking does” and “Yes, they go together -- eventually.” I needed to have it clear in my mind; I did not need it to be clear in his. There seemed to be nothing but wackos out there. But I wouldn’t, from the powers that be, take no for an answer.

Once, when I visited Jeff, I told him how I’d been feeling -- no mention of actual guys, just that I was sad, felt like not a “regular human being”, and as though I weren’t pretty. And Jeff, that time, said, “You’re pretty. I think you’re pretty.” Sad.

To down-size my worries my accountant and I decided to file taxes separately. Jeff and his helper tried to stop that; it would mean a loss for Jeff. I received a phone call from them. “Just thought we’d let you know: The tax accountant said that if you file separate it’ll cost a lot more, and he said to call you and tell you that.” I doubted that. The

accountant and I had already thoroughly discussed everything, and he wasn't the type to change his mind; if he had, he would have been the one to phone me. I speculated on what might have happened. He might have said to them, "Marion wants to file separately. If you want to file jointly, you can call her and discuss it with her. As far as I'm concerned..." No, the accountant was on my side, I tried to reassure myself.

But I was used to Kafkaesque. "I'm afraid the accountant's gonna refuse to do my taxes," I told Freda. "I'm sure he won't," Freda answered.

"You don't understand," I said. "The way things have been with me, I EXPECT the system to completely do me in. Last week.... well, I'll spare you the details but Jeff and his helper phoned me to tell me more mishegosh about how they don't understand why the money's not going into the joint account and... it just drove me crazy. He's demented. And he's allowed to hurt, and harm, me and Devin. I called four professionals at Inglis House and of those four, one called back. One." I described for Freda the messages I had left. "In the tone of voice I'm using right now," I finished.

"I see," she said. "Not hysterical. Well, your accountant will do your taxes." She tried to assure me. But I was not assured. A well spouse is never assured.

Devin told me he was thinking about writing a story, an autobiography, perfectly true until the very end when Dad would get better but his mind would still be all messed up and he'd come home and kill him -- him-Devin -- and he'd kill Jack, too, and also Marielle's new baby. He said it; I didn't. And I hated the system for making things such that Devin would think about writing a story like that.

I kept being on the lookout for men. I had discovered from David how much I loved being in love and I wanted it again. I truly and fully and correctly believed that I had the right to a second chance at happiness. And I heartily believed that a second chance at happiness had a right to me. Eventually I began saying just that in my online profiles, along with the explanation of my well spouse situation. I used similar words as on David's and my first date, and on several first dates with guys I met online. Then I made three points: (1) If I fell in love, I would be available for marriage or life-commitment. (2) What I had gone through had not made me emotionally needy in any way. I'd want my partner to appreciate what I'd gone through and treat me special in certain ways, but I'd be just as appreciative of whatever my partner had been through and would treat him special in certain ways. (3) What I'd gone through had not made me afraid to love again; on the contrary, I was determined to. Some people, including Suzanne, had said that guys probably wouldn't "get it", and would be turned away, but actually I had several nice responses to these ads, though nothing that worked out.

During that "bad year" I felt, correctly or not, that I had lost everything -- not only specific things like my love, my job, another love, and my book of math poems, but the entire universe as I'd known it, as most people know it, a universe governed by certain natural laws and by laws of probability. I tried to make something go right. But every time somebody said to me, "Tomorrow things will improve," it seemed that "tomorrow" something else bad happened. Indeed, big and little things kept going wrong during that "bad year". I wasn't imagining it. My therapist said, "I don't know why, either. But I do know that you're doing the right things and having the right attitude. And I think that

eventually this will lift.” Still, I felt as though the powers that be were taunting me. “Why fight it?” they were saying. “Why fight this infinite famine?” But I did continue to fight it.

Every time Jeff had a serious episode I visited briefly and to every new staff I explained our family’s situation, in particular why I was no longer visiting. Marielle often wanted me to call the funeral home. She wanted everything in place and she wanted me to be the one to put it there. I knew from talks with former well spouses that funeral homes get called after the patient has died, and it doesn’t take long to make funeral arrangements. But Marielle was anxious. I understand that now better than I could then.

Jeff had had a hospital episode while Marielle was on vacation. He had been “unresponsive” for a day or two but then came around. I had decided to not visit him this time. But Marielle begged, “Please visit him.” I understood but felt manipulated. If a guy I didn’t love told me he’d commit suicide if I didn’t marry him, I still wouldn’t marry him. This wasn’t quite the same thing but what the two have in common is, both are intrusions into one’s private life. I have the right to choose how to proceed in a relationship, especially when that relationship involves abuse.

It was hard to decide what to say to Marielle, but I was pretty well-versed by then. “As I said before,” I began, “I really am trying to act in such a way as to make things easier for you, but I also need to do things in a way to make things easier for me. I’m actually going crazy with all this.” Yes, we were both very fragile in those years.

But I did wind up visiting him. And I hated every minute of it. During this period I felt as though I was banished from humanity; I’d lost, not only the laws of nature, but maybe also the laws of math. Something was weird. I felt exiled, excommunicated from some-

thing. I continued to hope. I continued to try, to go places, to write and send in my work, to teach well. But I was aching.

On August 10, 2001 (the day after our anniversary, which went unmentioned) Jeff was five days into an unresponsive episode. “Jeff,” I’d say, every visit, “Hi. It’s me. I’m here. Do you know that Mar’s here.” He didn’t bat an eyelash. As soon as I walked out the hospital door, I’d utter “Yes!”, softly but firmly. Ditto when I phoned the nursing station and they answered my questions with “the same”. Enough of “the same” could lead to different. But alas, my own condition was also “the same”.

People who have been tortured are nervous. At the slightest provocation I felt afraid - afraid I’d forgotten something, or it would *seem* as though I’d forgotten something, afraid to check email, voicemail, my appointment book. Of course, one date out of that terrible period of my life began a terrible period in the life of the entire world. I was thriving on that day, and teaching the next. I greeted my algebra students with, “Well, do we want to talk first?”

Indeed “we” did. The students were upset and angry. Some blamed the Afghani, some didn’t. Some began to get loud over their disagreements. My experience in life-stuff helped me handle that situation. “Listen,” I said, “here’s what I think is the bottom line: We’re all just-plain SORRY it happened. We wish it didn’t happen. And we’re grieving, we’re in the very beginning stages of grief. I know something about grieving because I’ve had other, personal things to grieve over -- perhaps you have too. We’re all together in this grieving. We all agree that we wish it didn’t happen.”

They listened and quieted down. And I continued to grieve 911 but sometimes felt alienated from other 911 grieverers. Several people had posted on the online Well Spouse Bulletin Board, "After 911 I realize how insignificant my own troubles are". I wrote back "I disagree". I did not feel that my "own troubles" were "insignificant". For one, I believed there are connections between collective tragedies and personal tragedies, such as: the obstacles to personal happiness are, at least in part, the same as societal obstacles to collective happiness. I also felt that "realizing how insignificant our own troubles are" is part of the guilt trip that is laid on well spouses, also the same collective guilt trip that, ultimately, causes oppression, war, and other human-created tragedies. Also, just as Americans don't know or want to know what poverty in other countries (or in their own country) is like, so they don't want to know what at-home caregivers do, nor what happens to the families of people who have unofficial dementia. Sometimes when I ran into somebody and asked "How are you?", that person would answer, "Oh, trying to survive 911." How I wished that were the main thing I was trying to survive.

I think back to those times, the beginnings of what we're still living with. I see that I was trying to make sense of it all, my personal struggles and the world's struggles, striving to connect the two, making some headway. I remember yet another bad happening in my own life, albeit short-lived. Three days after 911 as I was checking my email I was, as a friend later observed, in "automatic mode". And so I took seriously an email whose subject line was "Save your AOL account". All I had to do, it said, was send within 24 hours the information asked for and my account would not be discontinued. I provided passwords, credit card number, social security number, even my mother-in-

law's maid-en name. As I was doing so I thought, plaintively, in my downtrodden mood of those years, "But AOL said they wouldn't ask for my password." Feeling betrayed by so many, I was assuming I was also being betrayed by AOL.

When I phoned AOL I saw they had not betrayed me. They immediately changed my password. Then I changed my VISA card number. Cathy told me I should call Social Security, otherwise somebody might try to steal my identity. But I felt as though my identity had already been stolen -- my identity as teacher, math-poet, lover, and human being -- a REAL human being, one who wasn't so beset by "too much grief, too many injustices".

Marielle had been talking about Hospice. Jeff would get more services, so would our family. I'd known Jeff wouldn't agree to it, but I told Marielle that I'd talk with his doctors about it. Soon afterwards Jeff's helper phoned me. "What's this thing about hospice?"

"Well," I answered, "he could get more services." But the guy was upset, and seemed to think I could help him feel less upset. I knew I did not need to be caregiver to him as well as to Jeff. Nothing I said seemed to calm him down, and I wound up saying, "Couldja please just leave me alone. This is hard enough as it is."

Around Christmas 2001 Devin and I went to see the Light Show, as we had done every year since his birth. We always basked in its wonder. But this year I wasn't basking in any wonder. Additional things had gone wrong in the past two weeks; the job that Bryn Mawr had interviewed me for had disappeared (lack of enrollment for the course; they'd been very impressed with me but the job didn't exist); I'd had a date with somebody non-wacko and he had decided that "it feels more like a friendship". I just couldn't

get into the Light Show spirit. I tried, in particular tried not to keep talking to Devin about how I felt, but my heart and soul were aching so badly.

“Once upon a time,” began the Light Show, “a little girl named Marie was given a nut cracker” -- No she wasn’t, I mouthed bitterly, already bathed in tears. Devin probably didn’t overhear that, but my feeling had spread to him. “That wasn’t any fun,” he said afterwards, and my heart and soul ached even more. “I think of you,” Devin continued, “not as someone to have fun with, but as someone to feel sorry for.”

“Dev,” I said later, hugging him. “I really really really want to give you my happiness. I want to give ME my happiness, too. But for now I’m giving you THESE instead.” I handed him the birthday package containing the new metronome and the jazz piano book I had bought for him. Oh, I tried, I tried so hard -- to be a good mother, to handle those almost-two years with grace -- but I couldn’t always succeed, not all the time.

A few days later, recovering from the latest bad-luck episode by singing and playing Christmas carols at the piano, I heard the phone. It was Jeff and his helper, and the upshot of it was that in one year Jeff would “max out”, meaning that his insurance had paid out a million dollars for his stay at Inglis House and would pay no more. If he didn’t die within the year, we’d go on Medicaid. “He has to die within the year,” I told Freda over the phone. “He just has to.” Then I added, “I know I sound not like a human being.”

“Oh,” Freda answered, “you sound VERY MUCH like a human being.” Thanks, Freda. On December 26 Marielle gave birth to sweet little Shane Anam. Holding the baby brought me much pleasure and took away some of my pain. Shane had a certain

distinctive look. He was very very lovely, calm but alert, happy and friendly. I was smitten, and Shane and I quickly bonded.

On New Year's Eve 2001 I was home alone. That was okay. It felt nice and cozy, quiet and warm. As I prepared Linear Algebra lectures, I even felt a little magical. It was one day before my fifty-ninth birthday, five days past Shane's zeroth birthday. I thought about all the other things that had happened in the various Decembers of my life, and about all these neat December outfits bought at thrift stores. Possibility was in the air. Maybe the computer upstairs contained somebody special in my email. Just a minute before midnight the phone rang. It was too late for that to be anything promising. I didn't answer it, not because it might be a crank call but because it might be Jeff or Fred.

No, the New Year didn't bring anything new. Everything was "the same". I was offered a full time job teaching physics labs and I knew I couldn't take it. I didn't understand physics the way I understand math, and I wouldn't teach it well; I can learn new math subjects in order to teach them, because math is my field; physics isn't. The whole thing made me shaky and fragile. Then one of my well spouse friend's husband suddenly died. All the well spouses were leaving me. "The cheese stands alone".

On January 22, 2002, I phoned Inglis House, inquiring how Jeff was doing. "I'm not allowed to discuss Jeff's case with you," I was told, "due to requests by Jeff".

Nothing surprised me any more. And as usual I wanted to make things clear. So I explained again, ending with "I know there's nothing you can do but the way I see it, the

system is taking very good care of Jeff -- and that's fine -- but it's not taking very good care of Jeff's family."

"I agree," said the doctor, "but there's nothing I can do." I had already said that, and felt annoyed. "Thanks," I said. "Well, bye."

But I got a nice email from a male well spouse whom I'd met at one of the Weekends and whom I'd suspected was interested in me. "Dear Marion: You are tall and attractive and intelligent. At the Tyler Park Weekend you had an enticing and seductive manner that interested me right away. Don't worry, I know you're not interested in me, and I respect that. I just want you to know that, if I was attracted to you, other guys will be also. Guys might be hesitant to approach you because of your intelligence and strength. Do you mind if I offer some advice? If you see a guy you like, you can make the first move and call him. Guys LIKE that." I thought that was sweet. Another well-spouse whom, via the Bulletin Board, I had helped with my ideas, also flirted with me. "Hi," he emailed, "I am Jim. You have been so supportive of me. I am glad of that. Tell me something about the fine Maid Marion." But he turned out to believe in capital punishment. Still, all those interested men, wacko or not, helped keep me sane throughout "the bad year".

Friends were also helpful. "Marion needs a biiiig hug," Cathy would say to her little daughter Stephi. But the hug I needed was a full-body hug, a man-hug, a foreplay-hug, a sex-hug. And around the end of January 2002, some of my friends were getting as tired as I was of "the bad year". Kathydeck even said "God never gives us more than we can handle", but quieted down once I said "What about the holocaust?" and "That's why I wish I weren't able to handle so much". Another friend said, "You know, you're not the

only one who's going through hard times." And Phyllis, over several conversations, expressed surprise and regret that I couldn't "simply let all this slide over you like water on a duck's back" or view the cup as being half-full. She said she wished I was simply "a strong woman". I didn't have a quick answer to that one, but I hope that my writings, in particular this book, have provided a *slow* answer. I hope they convey that I am not simply anything. I believe that I *am* a strong woman, but not *simply* a strong woman.

"Keep courting situations that are affirming," said my therapist, and I did. Teaching, friends, thrifting. I got a letter from a reader of "Dirty Details". "I think you are the only person in the world who knows what I am going through". I kept hoping for more things like that, as well as things that would truly make a difference in my life.

I was a basket case when I got another call from Inglis House; Jeff was closer than we'd thought to maxing out on his insurance. We would be going on Medicaid. But I also kept my perspective, knowing that probably nothing would actually happen with Medicaid for quite a while; that's how these things are. I'd be off the hook at least temporarily, and I hoped that, before Medicaid was in place, Jeff would be dead. The whole thing had felt like a race for a very long time, and now the race was getting close.

I want you to understand that it was not a fairy tale I was seeking but reality. I was seeking, again, the laws of probability, of averages, of cause and effect -- for good and for bad, not only good. Yes, it was reality I craved. I also want you to understand that I was not waiting for some man to rescue me. I was waiting for *anything* to rescue me, to respond to my active seeking. I was seeking a man so that's what, logically, I should get. When things are down, even a strong person regresses and wants to be rescued,

by something wonderful to happening. At least this strong person did. Suzanne understood -- that I was not paranoid, not delusional, not self-centered; my feelings and ways of expressing them were healthy responses to how my life was going. I kept needing to make sure my therapist believed that, and now I need to make sure my readers do.

I saw the film "Iris", about the mystery writer Iris Murdoch, her marriage, non-mono-gamy, eventual decline and death from Alzheimers. It made me cry, a lot. I cried for the same reason that others in the audience were crying. I also cried because I was crying, crying in relief -- relief that I was crying as a regular person and not as a well spouse. I was not angry that he kept her home and took care of her as long as he possibly could, then visited her continually in the nursing home. I was not skeptical of the extent of his love for her, as I was and still am when some well spouses talk about the love they say they feel for their ill spouses. I was not feeling harsh, uncompassionate, insensitive to the suffering and beauty of age, illness, dying, and death. I was not identifying Iris/John with Jeff/me. How relieved I felt to realize that, after all I had been through, I was still normal -- capable of living a normal life, if and when such a life would be mine.

No, I was not lying around waiting to be rescued. I was *running* around waiting to be rescued, waiting for nature to do the part of the rescuing that I was powerless to do. I used my savings from the Drexel job to do major house renovations. I had the contractor remove some of the many pilasters (all the same) from the second floor; now things looked trim; pilasters were not in corners, only framing windows and doors. On the first floor I had the ceiling stucco replaced by smooth sheetrock, florescent light replaced by recessed lighting, and crumbling kitchen counter tile replaced by something smooth and

white. *And* I was getting rid of the stairglide! No more huge wobbly non-working fraying seat cluttering up the stairway. Upward mobility. I was making sure I got it -- at least in ways that were in my power to get.

Sometimes Jeff would phone me. In a weak rasping voice, word by word, he'd ask, "Can-- you --tell-- me-- why-- you-- haven't-- been -- visiting -- me?" First I'd cover the receiver and sigh in frustration and weariness. Then I'd answer, in a sad, compassionate, but matter-of-fact tone, "Jeff, I've already told you, several times, but I guess you don't remember: You've been verbally abusive to me, you've accused me of stealing your money, you've withheld some of your salary from Devin and me."

"Oh," he would say, barely audibly. Suzanne told me she was "flabbergasted" that Jeff was still alive and that, in all her years of working with chronic illness, she had known no one who had to deal with it so long or so much. I, however, had.

Jeff had a new helper. I'd never met her and only from the kids did I know anything about her, in particular that she was upset about the way "his family" wasn't visiting him very often. When it was necessary, I talked with her over the phone; the first time I explained, again, why I was not visiting Jeff. "Oh," she said, not really listening. "I'm an old hand at caregiving. It doesn't bother ME. MY husband had A.L.S. I know what caregiving's about." Well, it turned out her husband had died three months after diagnosis. "She knows what caregiving's about," I murmured sarcastically, later, to friends.

Once she phoned me about Jeff's insurance; there was some information she needed. "And also," she added. "Could you do me a favor? Could you ask Bret and Devin to visit him?" She meant visit more often. She wasn't taking into account that Bret,

Devin, and I had already discussed the visiting situations among ourselves, many times over. Besides, it was none of her business.

Another bad thing happened. My neighbors and I got letters from the city saying that our real estate taxes would be raised -- a lot. Mine would more than double. Center City Residents Association scheduled a hearing at City Hall. I went to that meeting and told my story. There was a second meeting, to which I couldn't go because I had classes to teach. So I emailed Center City Residents the following:

“Good morning. I was at the meeting last Thurs., and I wish I could go to the the meeting tomorrow, but I have to teach my classes. I'm wondering whether somebody could say something in my behalf. Here's what I have to say: I have lost sleep over all of this. The over-100% increase in my real estate taxes could make or break me. I am in a situation which is in some ways usual and in some ways unusual, perhaps unique. The more typical aspect of my situation is that I am unemployed; as a college math prof, I was laid off from my full time job a little over a year ago (because of budget and other changes, not because of my performance on the job). I am now teaching part time... Of course, I don't get benefits, nor pension plan. My annual earnings are approximately \$20,000. (Almost \$9,000 in real estate taxes will be close to half my income.)

“The unusual aspect of my situation is that my husband has a very advanced case of multiple sclerosis and has lived in a nursing home for ten years. He used to contribute his disability payments to our family (which includes a child still living at home), but a year and a half ago his condition, which has involved cognitive loss for some time, got

VERY cognitive, and he did what people with cognitive loss often do concerning money: he obsessed over it and withdrew his disability payments from our access; only with the help of a lawyer was I able to get child support payments. Considering what I had to pay the lawyer, this settlement has not yet begun to pay off.

“Also, I do not have the option to sell my house, because my husband could legally stop the sale, and he has the same obsessions with respect to the house as he has with respect to money. So if I can not afford to pay the taxes on my house, I will simply lose the house (and the money to buy or rent another one).

“I feel that I have been more than a good citizen. I have done above and beyond what a good citizen does. [Here I made a list of what you already know.] In short, I have done what a citizen does, which is to go on being a citizen and to give what she has to give to the community -- and I have also done, and been asked to do, above and beyond that. I have also paid my taxes. However, this extreme increase I’m not sure I’ll be able to pay. As I said, I am losing sleep over all this.”

I continued to pursue the personals, keeping my well spouse situation in my profiles. A typical response ran, “.. I feel connected to you having spent some years in a similar situation You have obviously grown strong and that is to be admired. Rather than write further on the unhappy, let me say that your words as well as your photo show a woman with a lovely smile and an inner joy. ...” Some of the responses were from other well spouses. Most of these well spouses were not looking to leave their situations; some were looking for meaningful relationships “on the side”; others were looking for friendships. One wanted to have, forever, a “long-distance relationship”. “Some of the best

relationships are long-distance ones,” he wrote. I wrote back that I wanted a good *life*, not only a good relationship.

I wanted, wanted, wanted -- love, full time job, Jeff to die, the law of averages. “Dev,” I once said, when I was feeling all this especially keenly, “don’t let anybody tell you that your mom must not be a good teacher. I know it seems that way -- ya know, Drexel letting me go, no other full time job. If I hadn’t been a good teacher, they’d’ve let me go after one or two years, not four years. And it’s the economy that makes it so I don’t get another job -- Remember last spring? I got another job but then it went way. I should show you my letters of recommendation, saying what a good teacher I am. Don’t ever let anybody tell you that your mother’s a loser; she’s not, she’s a winner.”

How many downtrodden or disadvantaged parents scream, or want to scream, something like that to their kids? How many such parents know full well that there is nobody else to scream, or tell, that to their kids? How many parents know that, at least temporarily, while the kids are still young and impressionable, their disadvantages will be perceived by them as being the parents’ fault?

“Dad didn’t betray us because we’re bad,” I continued. “but because he has brain damage.” Dev had to know all that, and I was the one who had to tell him.

Around September 2002 I developed back pain. A few tests and I was diagnosed with scoliosis. I had P.T., which took care of the symptoms, and still does. During this time I also got a phone call from my GYN. I had, and have, osteoporosis. Again, not serious; I take Actonel. Then I had a bad persistent cold and sore throat, phoned for an appointment with my regular doctor, got one with whoever was on duty. A young intern

felt the left side of my neck, noticed “something different on the left side”, got all riled up, started talking cancer. The “bad year” had gone on for almost two years. Why not cancer? Come back in a month, she said; maybe it was just the swelled throat not quite healed. That month was like it would be for anybody, except that I kept thinking, “I can’t die NOW. I have to have my chance. I have to be allowed to at least TRY.”

My regular doctor eventually cleared things up. “Cancer is the very last thing that comes to my mind,” he said. Of course, neonatal death had, back in ‘77, been “the very last thing that came to my mind” while I was in labor with Kerin, and since then many other bad things had happened that had been “the very last thing on my mind”. Still, I immediately heartened. And soon I had a clean bill of health again, and my chance.

By then it was November. And on November 17 it ended, the bad year. It really -- I probably pinched myself -- ended. I got *the* email. Suddenly, suddenly, there it just was: Jon on my computer screen.

That was all I needed and wanted. Something, the best thing -- for me at that time, and for this time too. The thing I had sought, earned, deserved. The thing that I’d hoped the laws of cause and effect would kick in, that probability would indicate, the thing that would give me back my citizenship, and reality. Or, simply, the thing that has made these last four-and-a-half years an era that I wish would last forever.

CHAPTER XV: BETTER DETAILS AT LAST

“Dear Marimax,

“What a pleasure to come across your profile! I too am politically left-leaning -- though not as active in recent years as I used to be. That is partly because I got caught up in making a living and family (an old story), but also because I have not been able recently to find an organization or activity that I could really commit myself to. Have you been more successful in that? It has not been looking good for lefties for some time of course, but I really feel that the whole world has been away from it too long. (Or have I been indulging in nostalgia for the 60’s and 70’s too much?)

“Your work as a math prof is a somewhat more distant connection, perhaps; my first job was as a philosophy (assistant) prof, and my main strength before getting interested in philosophy was math. I still have a sort of amateur interest in philosophy, but for the last couple of decades have kept you-know-who from the door as a freelance Japanese-to-English translator, mostly of chemical and pharmaceutical stuff.

“Holding hands in ethnic restaurants sounds like a worthwhile way to spend time to me -- Japanese ones, given my interest in that area, but all sorts of others as well.

“Also, I’ve been trying in vain to figure out just what Marimax means. Sounds vaguely mathematical. I’m hoping you will solve the riddle for me.

“Looking forward to hearing from you soon,

“Jon”

This guy sounded non-wacko, my intellectual equal, very possibly emotional equal. It was only the introductory email, but already I began to feel as though my life had turned around. When I showed it to Suzanne, she said, "This one seems the best of all."

"Hi, Jon," I emailed back. "It was nice to hear from you, too. I'm not a very activist leftist, either, and probably not very political in general. I have, at various times, been activist in 'left-leaning-types Causes' like feminism and holistic health-care issues. And actually, this Saturday I'm trying to decide between two demonstrations, one in Center City (against Bush's war) and one in Harrisburg (against the death penalty). You probably remember the part of my profile that said that anti-death-penalty was a "pet cause" of mine and it's certainly a cause which I UNDERSTAND better than any other."

I asked whether he had a Ph.D. or other degree in philosophy, told him that existentialism and solipsism figured in a lot of my poems, also that I'd reviewed a book on the philosophy of math. "If you don't mind," I sneaked in, "I'd like to know your age, weight, height, how far from Phila you live; things like that shouldn't be important, but they seem to be." I also told him the solution to the "Marimax mystery" -- it's the nickname that my father, fighting in World War II, had for me when I was going on two; he had begun his letters to me, "Dear Maximax". I also suggested that we communicate via regular email rather than through the Metrodate site. Then I kept my fingers crossed that Jon wasn't too short, too fat, too skinny, too old, or too young.

I didn't have long to wait. He was six feet tall, 61 years old, non-smoker, and Buddhist. His Metrodate photo showed a very smiling strong looking person with a beard (and not much hair on top); he had the looks I like. His profile went: "I would describe

myself as kind, curious about people and life, philosophical, politically progressive, affectionate, and loyal. I am a busy freelance translator, divorced about 4 years, with 2 sons. I enjoy playing classical guitar, listening to Miles and Mahler, watching Kurosawa and Six Feet Under, meditating and growing in spirit, and quite a bit besides. I would enjoy sharing all this and more with an intelligent, independent, affectionate woman, as a friend, companion, and hopefully a long-term partner.” His opinion of tattoos was checked off as “ok, but not for me”. In looking for a compatible dating partner, physical appearance was “just one factor”. His favorite type of music was “classical”. Religion was “not important at all”. (Now, though, he’s a passionate atheist and I’m a very happy camper with that.) The quality that he valued most in people was “sensitivity”. The only-glich was, his friends would describe him as “low key”. I’m not low key but I knew that, if I had my choice of imperfections, low key would be what I’d choose.

The next day came his reply, beginning with “Yes, it is certainly better to communicate via regular email” and ending with “Where do you teach, and what sort of courses? Where can I see some of your poems?... And where have you been all this time?”

In between were the “vital statistics” mentioned above, his Ph.D. in philosophy from Yale, teaching for four years in Oregon. “But it became clear to me pretty quickly that I was just not cut out to be a teacher, and despite not knowing what else I could do for a living with such useless credentials, I quit and moved to the Philly area in 1970. After some movement activity and a couple of years in Japan learning Japanese, I came back here and started translating, which has supported me ever since, thankfully.”

He agreed with me about home-schooling and the death penalty. He was involved in starting "Movement for a New Society", lived communally in West Philly for several years, helped run a small worker-managed print shop, and was quite activist during the Vietnam War era. "The only remaining obstacle," I told Suzanne, "is how he takes it when I tell him 'where I've been all this time'?" I meant when I told him about Jeff.

I needn't have worried. "I was truly sorry to hear about your ex's condition and your situation with respect to him. MS is certainly one of the worst illnesses one can be visited with; I have known one or two people with it, but not to a serious degree...." His email ended, "I feel that at some point I would like to switch from communicating by computer to voice; if you should get that inclination..." He gave his phone number.

At the time I had a very bad cold and worse sore throat, so I could neither phone nor meet him. With the other guys, that would have served as a built-in excuse to slow things down. But for him I hurried to get rid of that cold! In the meantime we emailed for a couple of weeks. I learned that his two boys were each a year younger than each of my two youngest. Tom, the older one, worked at The Point in Bryn Mawr, also performed as a singer/guitarist there and other places. Bryan, the younger, was still in high school; his current interest was carpentry. I was favorably impressed with the way Jon's kids were not following any prescribed path ordained for children of left-leaning intellectuals. "Take good care of your throat," Jon wrote. "I'm eager to hear what you sound like!" And a few days later, "Among the many things I haven't mentioned yet is that I'm also very interested in learning thrift-shopping from you. I don't do it very often, but I would like to sharpen up my skills in that area," and in the next paragraph, "Is there any-

thing you're into that I'm not interested in? I haven't found anything yet; isn't that amazing?" (Later we discovered Scrabble and cilantro. Also, in the other direction, Wagner.)

"Your reminiscences of your childhood raise so many things I would like to say, but again -- later, later! I'm glad you appreciate openness. It's a trait I have only quite recently acquired ... But of course it's not a trait I indulge in with everyone; I just feel that you are someone I can and in fact 'must' deal with on this basis....I might mention at this point, looking ahead, that there are a couple of events later on you might be interested in. I realize that it might be too soon to think about our getting together for them, considering that we haven't yet gotten together in one place for anything! But it seems to me that the process we are going through to get acquainted is so different from what I have done in the past that I really don't know what the proper protocol is at this point. -- At any rate, our guitar society is having its annual holiday get-together on 12/ 7, in Collingswood and my Buddhist Center is having theirs on the 14th ... It will be really exciting to... actually meet you..."

And finally, "It was great to talk to you last night. I won't say that I was having doubts about your existence (thinking of the topic of solipsism), but... Every since I started using a modem, I have had the sneaking suspicion from time to time that all the stuff allegedly coming into my computer and showing up on my screen is actually being manufactured by some sort of Cartesian evil demon somewhere, so I was glad to hear a human voice. But wait -- suppose it was actually a computer-generated digital 'voice'? ... Well, I guess my suspicions will be finally laid to rest Sunday? :-)"

On Sunday December 1 Jon and I finally met at a Vietnamese restaurant in Chinatown. Thinking about it now makes my mouth water for Vietnamese food! Of course I was nervous, but not like before other dates. This was someone whom I believed would work out. I remember what I wore -- a long Carole Little dress of black textured fabric, bought in a thrift store for \$2.50. When he walked in the door, I recognized him from his photo. But he looked *more* handsome than that photo, and I liked his sweater with the design of bright colors around the neck. "Hm!" I murmured to myself.

So there we were, on opposite ends of the restaurant. We walked towards each other and then he did the perfect thing: He gave me a hug. *Just* a hug. That felt great. Then we walked upstairs and sat down. And talked and talked. At one point we realized that the table next to us was rather noisy. Around it sat a Vietnamese family having a birthday party. (I smile as I write this, and Jon and I laugh when we remember it.) They put on a "happy birthday" record, which was quite loud. "Well, we'll just wait 'til it's finished," we mouthed to each other. But then the song played *again and again, and again..* We soon realized that it was programmed to keep on playing.

I'd never before had the kind of date where one or both of us says, "Let's get out of here". A block away was a hotel with a fancy lounge up on the sixth floor; we went there and talked some more. Our total talk time was five hours. Just before his train home I walked him to the station and we hugged good-bye (*just* hugged). Again that was perfect. "So next week is the guitar party," he said.

"Oh," I answered. "You STILL want..."

“Sure,” he smiled, with the intonation that I wish printed words could convey. To put it mildly, I was happy. When I got home there was a nice phone message from Marielle. “Mo-om! It’s 9:30, and I see you’re NOT HOME YET. I assume that means you’re out having a great time. Tomorrow morning you hafta call me and tell me ALL about it.”

On the ride home from our guitar party date I felt some second-date anxiety. What would happen when we said good-bye; would we kiss or what? But then I reminded myself that there really wasn’t much I didn’t want to happen! And yes, as I was about to get out of the car, he kissed me. “I’m glad you answered my ad,” I said.

“I’m glad you PUT IN the ad,” he answered. Then he kissed me again, the same second-date kiss. Then ensued a short conversation that was just awkward enough. “So?” he said. “Now...?”

“Well, we’ll be in touch about our party-hopping next week,” I answered, and he laughed, that very nice laugh, and said, “Let me know if there’s any OTHER thing you want to go to..” I thought that was pretty cute.

“Okay,” I answered.

“So?” he then asked. “Are you going to be very busy this month?”

“No!” I answered. “I mean,... well... YOU’LL be a regular working person but I’ll be free ‘til next term, the middle of January..” Then, afraid of ruining it, I got out of the car and began walking toward my house. But before I turned around, we both kept looking at each other and smiling. The next day I left Suzanne a phone message. I’d told her that if anything really wonderful happened, I’d like to do that -- would that be all right? Sure, she’d answered. So now I could, and did.

In 1977, after my baby Kerin died and I was trying to get pregnant, I was so anxious to be happy again --to go through the grief process but, as I said in a poem, to “be HAPPY while going through the grief process”. “I want to burst forth,” I had written in “An Ambitious Sort of Grief”. Well, that’s how I felt now. So I did burst forth. I told my friends, I told my sister, I told the Separation/ Divorce email group.

After our second date, the signs were all there. So, after conferring with Cathy, I emailed him, “How would you like to go thrifting with me on Wednesday? The ones I want to go to are these two in Darby. And there’s a nice little lunch spot between the two thrift stores -- my treat, since I asked YOU.” He emailed back, “...definitely....”

He bought seven sweaters, “The Joy of Cooking”, two tablecloths, and a CD. He’s not exactly my type of thrifter, didn’t exactly tear through the racks, but also didn’t hover over me, waiting for me to finish. At the bus stop we kissed. And kissed some more. We kept kissing until we heard the bus driver. “Hey, are you two waiting for this bus?!”

On the ride home a man came over to us. “Hi. I’m sorry, I don’t mean to disturb you. It’s just that... well, on the ride over I overheard you talking about prisons and prisoners [Indeed, we had been.] and .. well, I’ve been ‘inside’, and I wanted to say, but didn’t get the chance, that I was really glad to see that there are people who understand OUR side.” We invited him to sit down next to us and he talked some more. He’d spent ten years ‘inside’ and his wife had divorced him, but when he came out they had married again. “Oh, she’s my best buddy,” he told us. “And I’m fine now. I’ve been in therapy

and I realize... oh, a lot of things. We've got ten kids..." We talked awhile, until he had to get off. That bonded Jon and me even more.

A few days later, sitting in The Point where his son had done his gig, we sat close to each other, stared, fumbled, stared, fumbled, then finally said that we loved each other. It was wonderful and it stayed that way. I read somewhere that one of the things about finding the right person is, it's pretty near perfect. That's especially true if you're both therapied. Jon and I are both easy -- to get along with and to connect with. Jon made it very clear that he was interested in me; he pursued me appropriately, just fast enough, without seeming pushy or needy and, unlike David, he sustained that pursuit.

"Party invitation!" was the subject line of a December 16 email to my friends, and in the body of the email, "On Sunday, Dec. 29, 7:30 I'm having an 'indoor carolling' party at my house, and you're invited! As most of you know, we'll gather to celebrate the season and whatever else we have to celebrate; we'll eat, drink and eventually sit around the piano and sing (except for those who want to stay in the kitchen and eat; you'll have to HEAR us, though..). If you want you can bring food (Healthy food is especially appreciated, but we want to have UNhealthy food around, too!) and you're welcome to bring family and friends. I look forward to seeing you at this occasion. As some of you know, it was an annual event for many years running, then I discontinued it for a couple of years (during tough times), and now I'm bringing it back! I am happy to feel celebratory this year. I hope you are too." We had that carolling party, and everything that I, and he, had dreamed of. In March my Chinese fortune cookie said, "Others will take over now."

Throughout all this happiness the Jeff-stuff continued, but I didn't mind it very much. Whenever anything escalated, though, I'd worry. One day my lawyer phoned; I needed to sign another paper, something about allocating how much was child support, how much wife support -- no big deal but I still worried. Also, Medicaid was hot on the trail.

I continued to email with the Separation/ Divorce Group. On March 17 there was occasion to write: "how many of us are scared that somehow this impending war will prevent or halt these gains that have been so hard-won? Jon, my new love, keeps talking about this war, all upset 'n' all, and... well, of course I'm upset too, but I'd rather just not talk a whole lot about it (nor watch all those TV programs nor read all those articles). For one thing, I'd rather he think and talk about ME! (It seems as though men, even if not ENLISTING in these wars, nonetheless get all-excited about them in some way...) For another, I've had about as much 'war' as I can take, meaning as a well spouse. I want to be 'civilian' for a while. [And indeed, at the annual conferences, well spouses often jokingly refer to non-well-spouses as "civilians".] Also, my ill spouse was always talking about various news items he was worried about and that brings back not-so-fond memories. How (independent of politics) is everyone feeling about these glum world-developments? Are we thinking about them at all?! If not, do we feel guilty about that? I just want this world to stick around long enough for all of us well spouses to re-claim. Please excuse these perhaps-offending thoughts, but: IS that too much to ask of it?! Are we being 'selfish' once again?!"

"Hats off to Marion!" was the subject-line of the next Separation/Divorce post. "I've had about as much 'war' as I can take, meaning as a well spouse... I am sick of it. If any

of us are prepared for war it is the remaining well spouses out there! We have been in bootcamp and all-out war for far too long. All I could think of is 'This damn war better not start before my [body-building] competition on Saturday!'... Thanks for making me laugh and showing me that I am not nuts... I also agree that war brings out the 'little boy' in all the men... It is in their blood... Marion, you're great; thanks for your honesty!"

"I fully agree," posted somebody else. "I'm completely battle fatigued and not at all interested in the news right now. The kids and I planted seeds a few weeks ago, and we're focusing on spring... a 'rebirth' of sunshine... and better days. Funny, Marion, my ill spouse is a huge worrier too, the weather, the war, money... However, he won't take any action to feel empowered about any of it -- it's so ridiculous. Thanks for sharing."

"Thank YOU," I wrote. "I actually felt a little hesitant before posting what I wrote yesterday, but it turned out to have been good for me, too, since it clarified some thoughts. Yep, it's spring and I'm in love and I have today off. I haven't known Jon long enough to know what his 'worry habits' are, over a period of time, but my ill spouse's sure were... well, worrisome! ... And you're right; the less these guys do, the more they worry."

Were we politically correct? Well, we sure were personally correct, and in solidarity.

One night, after a taco dinner, playing guitar, and correcting papers, Jon and I went upstairs to cuddle and read aloud from "the Wittgenstein book" (a long "biographical" novel about "big W"). Suddenly Jon had a pain in his lower left back. It could be just a muscle spasm, he said, from sitting the wrong way, but it could also be kidney stones; he reminded me of his two past bouts with them. He hoped the pain would subside but it

didn't. Around 10:30 he called his doctor and was advised to go to the emergency room of the nearest hospital. We walked the several blocks.

They took him pretty soon and concluded conclusively that yes, it was kidney stones. They gave him a pain killer and an IV drip. As it was dripping we talked, cuddled, eventually read the Wittgenstein book he'd brought along. And I thought about how successful our first-hospital-experience-together was. He was doing a great job of still being accessible to me, still being himself, not formidable, expressing whatever discomforts or qualms he had, allowing me to baby him but not over-dramatizing or self-pitying, showing his appreciation of me by holding my hand and arm and being extra-loving, and expressing concern for me, the sleep I was losing when I'd have to teach the next day. Moreover, it struck me how wonderfully strange it was to be at the hospital with a significant other who was not paralyzed, and who would get better.

I continued to be activist in the anti-death penalty and prisoner-sympathizer movement. One Saturday I went to a meeting of the Pennsylvania Prison Society. Most of its members were parents of people on Death Row. I talked with some of them afterwards. One woman said, "I was paying for a lawyer for awhile, and going without gas and electricity. But I have five little babies [her grands, children of her Death Row son and her drug-addict daughter) and you know, pretty soon somebody would have come and taken the babies. I told my son, 'I'm sorry'." The other woman I spoke with looked downtrodden; her son was one of the men whose death warrant Governor Rendell had signed. "Nobody told me or nothin'. I just heard it on the news and I tell you, I was fit to be tied." The first woman's son had gotten an unexpected stay of execution, and she

was relieved and happy. She had conducted the meeting with humor and humanity. We stood around for awhile. I had not expected them to be interested in *my* life, not in any big way. But I couldn't resist saying, "Ya know, I have a situation, too; my husband's been in a nursing home for ten years and... well, I see some parallels between your situations and mine, but I'd choose mine over yours any day."

They answered simply, "Yes, you SHOULD choose that situation." It felt both good and bad to realize that what we all agreed to was correct.

It was after one of the meetings of Pennsylvanians United Against the Death Penalty that Jon suggested we move in together. Of course I said yes. Excitedly we made plans. We'd live in my house; he was happy to get back into the city (and I was happy not to *leave* the city). Moving day would be July 1; we'd have a joint yard sale and a big move-in party. Jeff's and my mutual friends would not be invited, because I didn't want there to be any chance that Jeff would find out. I was sorry about that.

In late-July the kids and I found out that Jeff had been in the hospital for weeks. We had not been notified. I phoned Inglis House and sure enough, Jeff had decided to change his "next of kin". He had designated his brother, who lived out of state so not very available to Jeff. "Our hands are tied," the nurse told me. "Believe me, I understand completely," I answered. "I was also calling to 'touch base', to let you-guys know where we-all stand. I'M separated from him, but the KIDS aren't. They visit him, and they're upset when he's in the hospital for two weeks and they JUST find out. Also, I'm more than willing to be the contact person, and to visit him if and when he's ever suffering especially, or dying." Yep, there I was, explaining again. I was still a well spouse.

CHAPTER XVI : THE BEST DETAILS, UNDER THE CIRCUMSTANCES

In early August of 2003 Marielle left me a phone message that “Dad” was still in the hospital. It had been three weeks, significantly longer than his usual stays. The nurse on the floor had told her that he was “in quite serious condition”. “YES!” I called out while listening to the message. Soon it was four weeks that Jeff had been in the hospital.

Marielle was on vacation and she left me three messages: “I hope you’re having a GREAT time. [Pause] I visited Dad before I left and he SEEMED fine -- watching TV and everything -- but the nurse says there’s something with his heart valve. Could you try to get Arin and Bret and Devin to visit him.” Second message: “I’m having a GREAT time, and I’m anxious to hear how YOUR vacation was. [Pause] I’m also calling about Dad. Could you find it in you to call the hospital and see how he’s doing...?” Third message, a day later: “Mo-o-om, how’re YOU? I haven’t heard from you yet. I guess you’re busy unpacking from vacation, or whatever. I’d like to hear from you. I’m wondering whether you had the chance to call the hospital...”

I had spent the day deciding that I did not “have it in me to call the hospital”. I was angry that Jeff had changed the contact person, upsetting the kids so much. I’d had it anyway, and there seemed to be nothing more I could do for him. Also, I didn’t feel like explaining to the hospital people why I was suddenly calling after all these weeks.

I was finished being Jeff’s wife but Marielle wasn’t finished being Jeff’s daughter. Jon remarked, “Well, we can’t let our kids order us around.” He had also admitted, smil-

ingly, that *his* kids sometimes ordered *him* around. “But they don’t tell me to call the hospital when I don’t feel like it,” he added, as a joke.

Immediately after receiving Marielle’s third phone message I called her. “I had a wonderful time at Rehoboth,” I said. “And I’m glad to hear that YOU’re having a wonderful time, too. Jon and I were really really busy with contractors yesterday, so I’m sorry I didn’t call you back right away. And about Dad: Well, to tell the truth, I actually DON’T have it in me to phone the hospital. I did leave phone messages for both Arin and Bret.”

“Good,” she said.

“I’m just up to my neck in this business,” I continued. “I feel that enough is enough, and mostly I’m angry, or annoyed, at Dad for this contact person business and... well, there’s really nothing else I can do for Dad. At this point, I really do think it’s easier for you to call the hospital, if you want to...”

“Okay, I’ll call,” she answered. I detected an edge to her voice, and of course that would be understandable; I realize that more now than I did then. In fact, I’m not particularly proud of that particular incident. I now feel I should have called the hospital -- but I-now feels very different from I-then. And I want you to know that I-then came around very quickly; I did wind up calling the hospital.

The next day I got another phone message from Marielle. “Mom, I... Shane, close the door. I... Shane, let mommy talk on the phone. Mom, I... I’m sorry to be calling you but... I can’t handle this; I’m on vacation and... I called the hospital and they said Dad has to be on a respirator and he can’t stay at Inglis House any more... so now we have to find a place for him... can you call me back?”

“Shit,” I said to Jon once her message was over. “Now maybe I’ll have to spend the rest of my summer vacation getting Jeff re-settled. And damn, I’m afraid. Like, maybe they’ll say Jeff has to COME BACK HOME. Of course,” I qualified, “I know they won’t. If Inglis House can’t take care of him, certainly I can’t. Can I? I mean, they KNOW that, right? ‘They’ didn’t BEFORE, but they know it NOW, right? I just think of the worst. And I’m afraid somehow it’ll be that you and I can’t live together any more. There’ll be some law or something.” That night, even in Jon’s sleeping arms, I felt scared.

Later the next day I got a call from the hospital. There was to be a meeting that very afternoon, and it was important. I arrived with my fingers crossed behind my back. Maybe this is *it*, I thought. In particular, it would not be a matter of getting Jeff re-settled. I also felt nervous about Jeff’s helper Betty, the one who didn’t seem to understand what our family was going through. And indeed, as Jeff was having blood drawn and I waited outside his room, there she was. As we stood she abruptly asked, “Why are you here?”

I was taken aback. “Oh, because... because I SHOULD be here.. because Jeff probably WANTS me here.. because important things are going on.. because I was ASKED to be here... because... oh, I didn’t even know about it until yesterday...”

“Why DIDN’T you know about it?” she snapped. “Didn’t Elle tell you?” I realized that, in her eyes, I was guilty unless proven innocent, so I just wandered off. A nice social worker led me to a waiting room, saying she’d come get me when it was time for the meeting. “He does want you to be part of this decision process,” she added.

“Okay, thanks,” I said.

She grinned. “He says he understands astrophysics better than women.”

I grinned back. "Oh, is he charming you with his humor?" Then I stopped grinning. "But I know him in a different capacity. I know him as a... as a spouse."

"Oh, of course," she answered. She gestured. "Impossible. Just impossible." I hoped she meant that. I needed her to. But she just nodded when I told her what Betty had said. I needed her to do more than nod; I needed her to ask me to tell her the whole story, to listen as I told it, and to agree with me. But she also told me that that morning Jeff had "taken a turn for the worse". And I thought to myself, "Yay! And double-yay!"

"I should go into his room," I thought, "just in case he dies later on today." Then I thought, Kafka-style, "No. 'Cause if I'm alone in the room with just Jeff and Betty, and if he dies, maybe she'll say I pulled the plug." I was rational, but I also knew, and know, that there was something metaphoric in that.

Eventually that day I briefly visited Jeff, for the first time in about two years. It felt weird to be touching his arm, while thinking about Jon. Weird to be telling him about my new USP position, Rehoboth Beach, my involvement with Pennsylvania Abolitionists against the Death Penalty, the June 13 poetry reading, Devin's college applications. Talking. News. All the while reminding myself, "Not Jon. Not Jon. Not anything of which Jon would be a corollary." Soon a nurse came into the room. She checked one of the pieces of equipment, then smiled at Jeff, saying "meow, meow".

"Is this some kind of personal joke?" I smiled.

"Yeah," she smiled back. "He's got nine lives, like a cat. He keeps coming in, practically dead, and then he gets another life." I laughed, thinking bitterly how I'd just the other day been writing that in my diary. "Meow, meow," she repeated; Jeff sported a

flicker of a smile. After she left I asked him, "Do you want to KEEP ON living nine lives?" Very clearly, smiling-ly, and maddening-ly, he mouthed, "ten, eleven..." Shit, I thought.

That evening I told Jon that, although it was my turn to make dinner, I'd rather not that night; it was "going out time". So we ate at Villa di Roma in the Italian Market and boy! was the food delicious. The next day we went, at my friend Sylvia's suggestion, to a flea market at 39th and Powerton, but it turned out to be nothing much. "Well, we've got the car," said Jon. "Do you know about any other flea markets?" In fact, I knew of Quaker City. Jon bought a T shirt and six books; I two long black skirts and a white lacy-knit top with long sleeves that "branched" out. Then we found a diner; Jon had a Greek omelet and I had sliced turkey on rye with potato salad and the best pickles. And then, caddy-corner from the restaurant, I noticed a new St. Vincent de Paul thrift store. Jon bought four more books, I found a white ceramic cake server, then we looked through the bric-a-brac and joked about setting up a "tacky room" in the house.

Several days later at the hospital we had a meeting without Jeff. Besides several doctors and nurses, Betty and Lurch were there. The doctors said things like "the vegetation is getting bigger, not smaller", "the medication isn't working this time," "the valve can't work", "it's like cancer spreading through his body," and "we're talking about futility." They used phrases like "untreatable infection" and "not a candidate for surgical intervention". I relished each sentence and phrase, but kept mum; it was my turn for my own "conspiracy of silence".

“The question is, what to do when catastrophe happens? I see three options: (1) continuous intravenous antibiotics, like we’re doing, (2) oral antibiotics, and (3) to... to just stop.” I took notes, for everybody who would later ask questions.

Betty and Lurch fought it. “Stop WHAT?” “You mean...?”

I just listened, inwardly jumping like a jumping jack and calling out “Yes!”, outwardly sitting calmly and, for Betty and Lurch, forcing a “pained”: expression. “Now,” said Scott, the main doctor, “if we’re going to ask Jeff which of the three options he wants, it’ll have to be right away, since there might not be time.” It all felt like a good dream. I asked Scott whether he had a minute to consult with me alone. So he stayed in the room and I gave my usual explanations. I also told him about Betty’s attitude towards me. “I won’t be judging anyone,” he answered. That, again, wasn’t quite what I wanted. I wanted him to judge Betty! Because not-judging Betty felt sort of like judging *me* -- just as, a year ago, judging Jeff competent had felt like judging me *incompetent*.

Then followed a shorter meeting in Jeff’s room. It felt weird, again, to be touching Jeff’s arm as the doctors said what they had to say. They were very soft-spoken and beautiful, I thought. At each of the more difficult words, I squeezed Jeff’s hand. “As you see,” began Scott, “there are a lot of people here, people who care about you... As you know, you have an infection on your heart valve... it’s been close to a month... now, you’re a smart man; you know... we can’t treat it... there’s nothing more we can do.”

“Well, I wouldn’t say NOTHING,” Lurch interrupted. “There can always be SOME turn-around.”

“Yes,” answered Scott. “That’s right. There can.” I froze at those words, hoping Scott was merely smoothing things over for Lurch, Betty, and Jeff. Scott then went over the three choices. And when he got to choice #3 -- “decide, ‘what’s the point of doing all this?’” -- Lurch had his answer to that question. “Well, the point is to go on living.”

“Jeff, tell the doctor what you want,” said Betty.

“Live,” Jeff mouthed. It was a matter of days versus weeks but I thought, shit.

“Okay,” said Scott. “I respect that and that’s what we’ll do.”

I wish I could describe the expression, or rather, expressions, on Jeff’s face as he was being told the news. They were expressions I knew well. Some were denial, some acceptance, and some sad. And there was one, sort of the same as when he’s in physical pain. All told, I recognized Jeff in those expressions and I felt for him.

After that fateful meeting the professionals quietly left, and I was in the room with Jeff, Betty, and Lurch. “Can I have some time alone with Jeff?” I asked.

“You don’t have to ask that,” Betty snapped. “You KNOW I’d give you time alone with him.” Then she muttered under her breath, “all of a sudden you want...” I was about to say something but then decided to simply shrug. They left the room. Jeff smiled at me. I smiled back. But it was only acting on my part. I acted a lot in those days. Now I sat down, kept my hand on his arm, acted the part of the quiet wife, everyone else bustling about but me just being there with and for him, telling him about Dev’s college applications and visits, and asking “Do you want me to talk about these things?”

After an hour I got tired of even pretending, and Jeff was now asleep, so I went to talk with Scott. First I asked whether he felt that Marielle should come back from her va-

cation. "Probably not," he answered, "but a catastrophe could happen any time, although then they'd resuscitate." Then I asked him the time-frame question. "Probably three-to-five weeks," he told me, "but it could be any moment. I go on vacation in a few days and if he's still here when I get back, after Labor Day, I'll be very surprised." I won't be, I thought. I gave Jeff six weeks, maybe six months.

The next day I phoned the hospital and the nurse said, "He's actually better today." That made my blood curdle. She meant *feeling* better, right? Or *relatively* better. Temp down or something. She couldn't mean a miracle. Please, no.

"It WILL happen," emailed Normie. I was sure she was right. But I fantasized phoning the hospital every few hours to ask, to check, "Is the vegetation still untreatable? Are we still talking about futility? Are you sure?" I *know* it happened, I thought, crazily. I know I didn't dream or wish it. I kept checking my diary.

Another week passed. On Jeff's birthday 2003 Marielle rounded up everybody to visit him, at different times during the day. Marielle and I at 11:00 AM., Bret and Devin at 4:30 PM. Two days after that "Dr. Scott" would return from his vacation. He would be surprised to find Jeff still alive. Whenever the phone rang I thought, maybe this is it. Then, when it wasn't, so what happened to his dying? Did nature forget about that?

I wrote to other well spouses, and to the Separation/ Divorce Group. "I will need your input and support in the next weeks. What I need your support about is mostly that I'm afraid it's not real but a false alarm, and I'll have to go through years and years (or MORE years and years) of this. I also need your support and input concerning the kids. They have NOT become separated from their father, nor have they acquired a new fa-

ther [as I have a new guy]. So they're grieving and upset in different ways from me. Besides, they're kids. So my daughter needs me to make it right, but of course she won't realize that it IS right. And my two middle alternative-style-non-relative-get-together-type sons are threatening not to come to the funeral. Jon is being very very cool, and that's the main thing. I'm glad you're all around. Love y'all."

Marielle was, understandably, anxious about the funeral. "Dad's" brother would be in charge of it. I was glad of that, but Marielle was upset. She wanted to know what his brother had in mind, where it would be, with what rabbi, and so on. I was more than willing to wait and find out. But "Don'tcha want...?" Marielle would ask. Or "Shouldn't we...?" Damn it, I thought, no. Let *her* try to find out.

Marielle and Bret wanted to have this week's Family Night in Dad's hospital room. I would go, too. I didn't want to. I was afraid of getting caught in the middle of further complications, or being blamed for something. When I was an adolescent beginning to date Jeff, I'd help my mother with the supper dishes. And sometimes, as I was helping her, she'd bring up something about Jeff, something she didn't approve of, something that made me uncomfortable. And I stayed. I kept on doing the dishes. I was always a good girl. I didn't know or believe I had the right to leave when she said something that hurt me. But *now* I knew; I would exercise that right if need be.

But it turned out that need didn't be. The kids seemed centered and calm. Everyone respected everyone else's feelings. No one even subtly attacked anyone else. The kids talked about the various songs "Dad" liked. Pretty soon I too was singing "Wild Thing" and "Mrs. Brown, You Have a Lovely Daughter". Jeff smiled. Marielle asked him

whether he wanted to be buried in Philadelphia or New Jersey. “Philadelphia -- yes or no?” He seemed to indicate yes. But Marielle said that an hour before, the same question had gotten the opposite answer. So I asked, “Jeff, do you know that, an hour ago, you said something different; you said North Jersey?” I repeated that. Jeff didn’t respond at all.

The kids were as anxious to leave as I was. We ate at Tandoor India, because we used to go there with “Dad”. In the car ride home, Marielle and Devin talked more about how they felt. It turned out that they all, ballpark, felt the same way I did. Marielle, in particular, talked about how dealing with “Dad” was impossible, the idea of it unrealistic, I was doing all I could and should do, it was not the be-all and end-all where “Dad” got buried, what he had done in re-designating his next-of-kin was really hurtful and interfered with the pure sadness. She also said she was trying to “let go of it” a little.

Some of my friends had various versions of wanting me to “feel connected with Jeff”. But that’s where I’d been two, three, five years before. I was past that now. Like the well spouse at one of our workshops I thought, “it’s beyond all that. ‘WAY beyond all that.’”

Jeff hung on. The infection spread to his blood; his heart rate went up and down. I was afraid somebody like Betty or Lurch would think of some new angle that might prolong things even more. But, armed with the almost-definite prospect of it all being over relatively soon, I was trying to let go of worrying. It was out of my hands, always had been. It was Jeff’s life, and his death. His and the health-care laws’.

“I think I’ll go away on a trip and come back when it’s all over,” said Arin. “Me, oo,” I said, though tongue-in-cheek. Maybe we *all* would.

During our phone conversations Normie and I cracked each other up. “I CAN’T WAIT!” I said. Yes, to her I could let loose completely. (To Jon I could too but he didn’t understand like Normie; he hadn’t been through it.) “I don’t want to wait weeks; I want it NOW. I can just smell that bouquet and I want to hold it in my hands.”

Normie told me about the Jewish custom of lighting a candle for eleven months to help the dead cross over, or whatever. “Oh,” I exclaimed. “I thought it was to make sure he STAYS dead!” And we burst out anew. Yes, I later thought more seriously, dead chronically ill spouses have to stay dead. Chronically and incurably dead.

I joked with other friends, too. “I hope that, at the next meeting, they don’t decide that he’s coming HOME. If they do, he’ll have to sleep in the guest room which is -- Oops! -- pretty filled up with Jon’s books, some unpacked, some not.” My sister said the whole thing reminded her of the Hitchcock movie, “The Trouble with Harry”, how the body couldn’t seem to get buried. We laughed at that, and a couple days later I found that video in a flea market. Jon and I watched it and laughed.

I was looking forward to the emotional downsizing. I began writing a eulogy. It would be a eulogy for *the kids and me* as well as for him. I’d begin by saying nice things about him (past things) and then I’d launch into Part II, about the kids and me. It would be “the family eulogy”, long overdue. And the longer the part about him, the longer could be the part about the kids and me! Was that attitude or what?!

“After all we’ve done,” said Marielle about “Dad” changing his next-of-kin. “I think about Arin handing him jars.” Yes, and Bret doing entire nights at the age of twelve. And

Devin's memories of being a toddler, realizing that Mom had enough on her hands, better not bother her with any requests. And Marielle arranging Arin's insurance for the same reason. Not to mention nights, lifting, and toilet for me. Marielle talked with me for quite a while about all that, and it felt so good. "What you're beginning to feel now," I said, "is what I've been feeling, full-blown, for at least five years." I told her again how "Dad" had put his entire disability check into his trust fund, then I went into more detail than before, how I'd tried to prevent it, had to hire a lawyer to get the support payments. "Ya mean, Dad didn't care about DEVIN?" Marielle was almost in tears.

"No," I had to answer. "In a way I feel ASHAMED. I'm sorry -- and I do apologize -- that you kids had to grow up with so much craziness."

It felt ever so good when Marielle answered, "I don't think an apology is needed."

One day I bought a ring at a flea market for five dollars, a pretty sterling setting with a light blue stone. But about a week later the stone fell out, no chance of finding it. That night I told Jon about it and he said to me, "I'LL buy you a ring." Hm!

At USP the math chairperson put me in touch with the Humanities Department. "I think Bob would be very interested in your poetry." So I went to visit Bob, we had a nice chat, and it wasn't long before I was invited to do a reading. It would be part of their Mischer Series, kind of a big deal, honorarium, out to dinner. I would read the math-poems, for sure, and well spouse stuff, in particular about the recent developments. Jon would be in them -- and present at the reading. I looked forward to that.

In late September Marielle phoned to tell me that the hospital was sending Dad to a rehab center to wean him off the special “bypass ventilator”. They had made sure to tell her that that didn’t imply anything about his condition; he was still in the same state of health. But to me it felt like more chronic. Would enough ever be enough? Was there such a thing as enough? “I feel disgusted,” I wrote to Julia from the Separation/ Divorce group. “All this crap they’re going through to keep him alive according to his wishes. I wish people would go through this much crap to go according to MY wishes. About ANYTHING, I mean.” To Normie I said, “It seems like however long I can last, that plus one will be how long HE’LL last.” We laughed.

The rehab place was far from us. Marielle and I felt insulted that the hospital hadn’t called us to let us know. But I was through fighting it. I would not get involved, not phone the hospital or go along with him for the transfer. I couldn’t do anything about his or everybody else’s decisions, but I COULD do something about my own. “The reason I’ve been visiting him,” I told Marielle, “is, this is near the end. And now it doesn’t seem that way; it seems to be going on and on...” She understood but shrugged. Jon and Suzanne understood and did NOT shrug. In fact, Suzanne left me the phone message: “Absolutely right. Enough is enough.” She also added, “Oh Marion, I’m so sorry. I can only imagine what you must be feeling.” To me that smacked of “He’s not dying after all.” So I left her another phone message. “Is there something you know that I don’t?” “Absolutely not,” came her answer. “This transfer is just part of palliative care.” Whew!

I told Arin and Bret that one of the things that was probably so hard on them was that they're the same gender as "Dad" so they might, at least sometimes, identify with him.

Then I said "Just because Dad's a wimp doesn't mean YOU are."

"Yeah," said Arin, "but sometimes it sort of feels that way."

On October 3 2003 Marielle phoned to tell me that "Dad" was being transferred to the Intensive Care Unit. "I have a bad feeling," she said.

I felt like countering, "I have a GOOD feeling;" but didn't.

Marielle visited him. His eyes seemed infected, she reported, all pus-y and red. And they wouldn't close. Also, he was not responding at all. The nurse was upset to look at him; it seemed as though he was in pain. Well, said the kids, it was his choice, to end it this way. Indeed, but that didn't help me much, as far as his seeming to be in pain went. That night I dreamt that he left a message for me with somebody. "You're selfish. I want you to come see me." But the next morning I kept to my decision to go to that flea market. The dream did *not* mean I was selfish, nor that Jeff wanted me to go see him. The dream meant that's what I was worried about. That, and what Jeff, Betty, Lurch, or the nurses might think. Still, I kept imagining bright red eyes that wouldn't close.

Some ill spouses are truly *Mensches*. They give their well spouses a "gift" by saying, earnestly, "You go live your life. Find someone who loves you. You've been there for me; now go live your life." Jeff had never done that. Not even close. And I wasn't holding my breath. There would be no "deathbed conversion", for sure. I was so glad I had taken my life without being given permission. I had given myself (and mine) that gift.

“Hi there, group,” I emailed. “Well, he ain’t dead yet. And from what I hear, he’s suffering and that bothers me.... The infection is ravishing his body, as the doctors warned; it’s coming out of his eyes.... Even my daughter is visiting him just once or twice a week, not every day. I’m just bowing out of the whole situation.... I’m satisfied that this long dying is progressing in the right direction, and excited about the actuality...”

On the morning of October 12 Marielle phoned to say, “Mom, I think you might want to visit him. I’m driving down; I can come pick you up if you want -- only if you want.” I got the gyst and felt appreciative.

Jeff’s blood pressure was down. So was his temp. His eyes had been sutured part-way shut. His stomach had stopped working. His skin was red, not beet red but apple red. And Marielle told me not to look at his hand. She covered it with the blanket. “It looks like it’s ROTTING,” she said. Morphine hastens dying and on the blackboard, in accordance with Jeff’s advance directive, had been written “No morphine ever”. Jeff’s brother, a lawyer, was enforcing that directive. “That’s what Jeff wants,” he said. Everyone else was horrified. Marielle and I just stood there, at first on opposite sides of his bed, then on the same side as we kept our arms around each other.

After awhile I asked Marielle to leave me alone with her Dad. Then I leaned over to his right ear and said, very softly, “Jeff. I don’t know whether or not you can hear me but: I... I want to thank you. Thank you for rescuing me from my adolescent loneliness, and... and for the good marriage that we had. For the fun times we had together, all the things we shared. And the kids. Thanks for the kids.” I paused. “And NOW,” -- I paused

again. -- "I think you should just relax and let go." I softened my voice some more. "Relax and let go." I repeated, more slowly. Then I said "bye" and left the room.

Marielle and I then went to talk with Dr. T. "We can't do anything," he kept saying, He and his team wanted to stop trying. "I feel so bad for Dr. Cohen," and to Marielle, "Every time I see you and your brothers I want to cry." They had repeatedly tried to convince his brother, but to no avail. Now they were bringing the matter before the Ethics Committee. They – in a *Catholic* hospital -- were fighting that advance directive.

I then asked Marielle to leave the room; I wanted to talk with Dr. T. alone. "Please, if you possibly can, if you're allowed to, please pull the plug. I can't begin to tell you what this is doing to his family. PLEASE, if you can, if it's at all possible, pull the plug."

That evening Jon and I went to a friend's wedding. We danced right up to the very last dance and partook of the Mexican vegetarian buffet. We got home around 10:30; a few minutes later the phone rang. It was Marielle, sobbing. "Dad died," she gasped, with a voice inflection slightly like a question. I could understand why. After all these years, all we'd been through, all those close calls, was this truly happening?

YES! I thought, gesturing behind my back. What I said was, "Oh, Elle. I mean, really? I can't believe it." "I know," she answered.

She had just gotten the call from Dr. T. And soon afterwards Betty had phoned -- very coldly, Marielle said. The funeral would be on Tuesday, two days later. I told Marielle that I was very glad it was Dr. T. who had called her first, and not Betty. We talked for awhile, very quietly. It was the end of an era, a very long era. It was a moment in time, an eclipse, a Big Bang, something almost precious in some way.

CHAPTER XVII: A FUNERAL AND A WEDDING

After hanging up I burst forth again. First I indulged; YES!!! Then I ran upstairs to where Jon was translating. Then I phoned Arin, Bret, and Roz, then Marielle again (to assure her I'd phoned Arin and Bret, and to see how she was doing). Then Cathy and Freda. And then Normie. She had said I could phone her with *that* news any time of day or night. Here's how the beginning of that conversation went:

"Uh... Normie!? Guess what."

"I'm going to send you RED ROSES." (And she did.)

The next morning I sent a mass email. "Something happened yesterday which, to me, means that today is truly the first day of the rest of my life. My husband died. All of you are friends who know what that signals the end of.... I have been fortunate in having friends who stood by me and with whom I can be honest, to whom I can say 'I'm soooo happy about this'. Not only relieved but happy.... I look forward to talking with each of you individually; this email is just to make sure that all of you know asap..." To the Separation/ Divorce Group I emailed, "YES!!! More so than ever before!..." I gave two pages of details, ending with "In struggle, and sometimes OUT of..."

"So," I quipped to Jon, "I'm single now; I can get engaged." The next day we went to that store two blocks away and got the ring I'd seen a couple of weeks before. It's got tiny amethysts, four circles and three diamonds (meaning diamond *shapes* -- yup, a ring with four diamonds, I joked.) in a very intricate pattern. I loved the way the stones were

sometimes obviously purple, other times more clear, depending on the angle. And the design lay low, flat, nothing bulky to wobble around to the underside of my hand.

So yup, I got engaged to my second husband the day after my first husband died. So what else was new?! Meaning, that seemed to be the kind of thing life often presented me with, so that was the kind of thing I presented back. And yup, the day after my second husband and I got engaged, we all went to my first husband's funeral. Jon drove Dev and me. Bret, Arin, Marielle and Matt were going in a separate car. "JON's going, too?!" my sister had exclaimed, over the phone. "Yup, it's gonna be a happening," I'd answered. I knew she understood. But on the ride there I began to feel a little nervous. What would people think and say about the presence of Jon? I also had brought along my "family eulogy". How would the reading of that go?

The service was, most people felt, an insult to Jeff. Very impersonal, done by a strange rabbi, not the rabbi who'd known him and his parents well. It was Sukkot, and this rabbi said that Sukkot is a holiday in which national celebrating takes precedence over individual grieving so you're not supposed to give eulogies, neither mine nor any other. I wasn't the only one who thought that was dumb. There was another thing, something I don't like to remember. The rabbi said, "...and then, of course, when he got sick his PARENTS, according to Jewish tradition, took care of him -- "

"NO!!!", I wanted to shout, and came very close, "THE KIDS AND I took care of him. His parents lived far away, and then in a nursing home. And his father had died. His parents COULDN'T have taken care of him. It means a lot to me and other caregivers that people know what actually happened." But I didn't want to detract from Jeff or upset

the kids, nor do anything I'd regret. Also, the somber austere atmosphere might have intimidated me. I thought somebody else might say something but nobody did. We all just let that service be. I still wish I had shouted out my protest.

The ride to the gravesite was rushed. The service had had to be held up because of a traffic jam and it was close to 3:00; the gates would soon close. On the ride over, gal-lows humor style, we were joking about what would happen if we didn't get there on time. "They'll have to leave the body by the side of the road 'til tomorrow morning Jon quipped. "Gee," I quipped back, "I hope they don't say I have to take it home and TAKE CARE of it -- ya know, caregiving... Yeah, not only dead-WEIGHT, but actually DEAD."

At the gravesite individual people, whoever wanted to, shoveled dirt individually into the hole. I hesitated. My sister came up to me and asked, "Do you want to...?" I decided that I did. Or rather, I wanted to make sure I didn't make any omission I might later re-gret. The shovel was heavy; I hadn't realized it would be that heavy. But not as heavy as *he* was, I thought, "when I had to lift him onto the toilet."

The day was meaningful, even if the service wasn't. First, it marked something -- everything. Second, it meant so much that Jon was with me. I felt so proud of him. Third, the kids and I saw relatives we hadn't seen in a very long time. I'd always liked Jeff's family. They had welcomed me from the beginning and appreciated the kind of person I am. Now they welcomed me again -- and Jon.

Next day was a much more meaningful memorial at our house. Beforehand, I relaxed at the piano, singing the Schubert Lied, "Death and the Maiden". It seemed close to "Death and the *Young Man*" and I cried, not in sadness but compassion, pensiveness,

and human-ness. Hours later Phyllis and I sang it together. Marielle then put on a CD of “Dad’s” favorite songs. Jon and I found ourselves dancing, until I caught Marielle crying. I went to her. But “No,” she told me, “keep dancing. That’s not what’s making me cry. I want you to be happy.” The atmosphere of that memorial was happiness, as many memorials turn out to be. But this one seemed happier than most. A long ordeal was over. And I got to read my “family eulogy”. Here is part of it:

“Two days ago I said the final good-bye to my husband Jeff. I thanked him for the life we shared, starting with his rescuing me from adolescent loneliness. I’ll never forget the day that I, itty bitty 15-year-old, boarded the 49 bus home from school and in walked this big tall handsome ‘boy’... the conversation we had, about math, in particular this book “Flatland”, which is a fantasy about life in a two-dimensional world. We met on that bus many times after that. It took him over a year to ask me out but he did.

“Memories: ...We talked about how someday we’d be ‘Dr. and Dr. Cohen’... (In those days we weren’t liberated enough to think ‘Dr. Deutsche and Dr. Cohen’.) We discovered Oriental rugs -- we liked non-symmetric ones with animals... Jeff also helped me get my PhD; when I couldn’t find an advisor he asked a colleague to help me get Laurent Schwartz, a world-famous mathematician, to approve my dissertation. It was a good marriage, based on sharing thoughts and feelings, and the love of science. Even before Jeff was diagnosed with M.S., we weathered a lot together. There were career disappointments, dreams and aspirations that couldn’t come true. We lost our third baby, a girl named Kerin. We grieved together, not apart. We were politically active, belonged to an anarchist ‘Art/ Politics Group’, went to alternative parenting meetings. Jeff

was active in the Sierra Club, and there were many meetings at our house - yes, when it became too difficult for him to leave the house, these meetings came to US. Jeff was very interested in and supportive of my "M.S. poetry", and of the Well Spouse Foundation. And he made sure (or tried to) that he got enough home health aide help so I could do readings and presentations at week-long conferences. One of Jeff's unrealized dreams was to get his solar collector marketed. He had invented a new type, which got around the problems of the existing types. His idea was written up in many newspapers and journals, won the Best Invention Award at the Franklin Institute, and captured the interest of many a would-be entrepreneur. However, for various reasons, no one was able to make the invention take off.

"All this is nothing compared to his physics. For starters, he got his PhD in three years, from Yale... His field was general relativity (ya know, Einstein); he spent two years at the Institute of Space Studies in New York, then two more years at the prestigious Institute for Advanced Study -- yes, THE Institute, in Princeton. Also on his repertoire: Courant Institute of Mathematical Sciences, Max Planck Institute, and the University of Pennsylvania. He worked with Banesh Hoffman -- who, besides being one of a famous trio which included Einstein, was the editor of the book Flatland that Jeff and I had talked about on that first ride on the 49 bus. Jeff could have been quite a name-dropper; Al Cameron, Dieter Brill, John Wheeler, Roger Penrose (of Penrose tiles. . .) and yes, Steve Hawking -- all were people whom he worked with and knew personally. Jeff had several PhD students, gave invited addresses all over the globe. And grants -- I added them up on my calculator -- we could all get rich on his grants.

“Jeff’s physics was world-renown. It’s he who initiated the concept, ‘rotating inertial frames’, and he’s the Cohen of ‘the Brill Cohen method’; also, it’s due to him that white dwarfs were abandoned as possible pulsar models. His papers total 106, all in important journals. He was most definitely an impressive figure and he’s left a lot in this world.

“And here’s where I get to say what I couldn’t say at the funeral yesterday, and what I wanted to say when the rabbi said erroneously that it was his PARENTS who took care of him in his later years. Jeff has left four children and he’s also left a wife who, though estranged and moved on to new love and happiness (Hi there, Jon. . .), will never forget her first love and the father of their children. At the funeral I wanted to talk about these left ones, what they went through. I especially need to acknowledge the kids, what they’ve had to endure all their lives, and the sometimes very subtle and strong ways in which they’ve survived. Devin never knew a father who could walk.... Marielle and Arin watched in bewilderment as their father changed, in mind and heart as well as body. And when Bret was twelve years old, he was the first to figure out the dials on his father’s new ventilator.,, To relieve the stress on me, Marielle made ALL the arrangements in getting early admission to the University of PA. I really can’t begin to describe the lives of these kids... lives which involve too much life-knowledge, too little innocence, too much responsibility (or FEELINGS of responsibility), not having a healthy adult male parent to identify with, not enough feelings of security. I just want everybody here to realize what Jeff’s and my kids have gone through, and also what I have gone through -- and for how long (namely, 26 years).

“I also want to tell you why we, in particular why I, visited Jeff less and less frequently

in the nursing home and why I separated from him and sought a new life and new love. There are several reasons: (1) Good things run their course -- things like love, strength, feeling connected, even the feel-good-ness of memories. (2) I feared for my physical and mental well-being. I had heard of other well spouses losing both. I also feared for my ability to be there for OTHERS, besides Jeff. (3) I believe that Jeff, although ill and suffering, is not the priority. Jeff's work in physics is not more important than my work in math and writing, or whatever work our kids will do. Jeff is not more worthy than his wife and children. (4) I believe that the kids and I have the right to, and deserve, happiness. (5) M.S. can affect personality and judgment, Jeff said and did very hurtful and harmful things to me and our kids (no need to go into further details). I know, in my gut, that Jeff was not to blame. I don't feel angry or vindictive, but I do feel that his betrayal of us needs to be acknowledged. I believe that failure to do so is tantamount to failure to acknowledge US. And I stopped visiting him in order not to be the victim of verbal abuse.

"It's also important that you know that, while some might feel that I 'abandoned' him these last three years, I did NOT abandon him for the other 23. I hope you don't mind that this eulogy is partly in honor of the kids and me. The whole family played heroics long before the heroics done by doctors for the past ten years to keep him alive. All six of us worked really really hard. And so, on this occasion of the end of a very long struggle, I'll end by thanking you all, very much, for being here and for listening."

Marielle came over and hugged me. So did many others. I had emailed that eulogy to those who couldn't be at the memorial and I soon received admiring emails back. Jeff's cousin Jana wrote: "Thanks so much for sending the eulogy you should have been able

to give... Jeff... deserved more in terms of commemorating his life. I am not a religious person and find the rituals often oppressive. Your eulogy was lovely and more than makes up for what the Rabbi failed to mention. I was always in awe of your inner strength and ability to follow what was important to you. You never seemed conventional. I was so glad to see that you seemed happy and obviously in love. I cannot imagine what it was like having to take care of Jeff all those years... I just ordered your book, which I look forward to reading... You must feel wonderful to have such a beautiful family. I didn't get a chance to meet your daughter, but your boys... were delightful to talk to..." Louise and Ian wrote. "Dearest Marion: It was with mixed feelings that we received your email. We share your happiness about Jeff's passing out of his pain-filled existence, but are saddened that this dreadful disease ever happened to you and your family..." Others also wrote variations of that last sentence and it was well-taken. Indeed, the tragedy had already happened a very long time ago. It felt weird to me that society could expect me to grieve something I had already grieved. Thinking about it now, it reminds me of the very beginning of the odyssey, when Jeff was first diagnosed; I had felt as though I was supposed to grieve something in the distant *future*.

The math chairman had given me the entire week off, even though I was part time, and I was grateful. He told me not to worry about my class observation scheduled for that Tuesday. ("Don't even THINK about it. You're doing very well.") I was not grieving but I had things to work out with respect to the funeral and the memorial, and I was glad to have "quiet time" with my family and my self. I had also emailed the Humanities Department; they had kindly given me the option to postpone the poetry reading but I told

them no -- that reading was extremely well-timed; I would read poems, not only about my well spouse experience, but about my recently-acquired *former* well spouse-hood.

The reading was another high. Jon was there and so was Marielle, taking a video and later presenting me with flowers. First I read math poems, then my recent “evil woman poems”, then I said: “And now what follows is a celebration, in the extended sense of the word, of a 26-year odyssey that my family, my four kids and I, went through and which ended just a week and a half ago.” I summarized the odyssey, and its ending. Then I read the MS poems, both very old and very new. Afterwards Jon and I were taken out to dinner at Thai Singha and we all had a meaningful conversation.

The following day was a memorial at Inglis House. The rabbi and pastor conducted it and gave everybody opportunities to speak. So I got to read my eulogy again. Bret sang “Song for My Dad” on his guitar, a very quiet and sweet piece that he had actually sung song to Jeff. Marielle then stood up. “I’ll TRY to say something... My dad was so POSITIVE, and he was DETERMINED to live, he really wanted to live, and... this is a very bad time for me right now... I really miss my Dad...” True, one of the aides said, “He never ever had anything but nice words for his family”, and I bristled. Most of the aides, recall, used to tell me how he never showed concern for his family, said I was a spend-thrift, and they knew about his financial abuses. And true, afterwards Lurch told us he wanted to “say a few words to the family”, and Marielle later told me that had worried her. But he had only wanted to say, “I like to think that he was a good wrestler because he was so smart, he pinned you without it hurting... and he NEVER had a temper tan-

trum. And I think that the reason for that is, he just thought of a way to solve the problem..." I whispered to Jon, "he didn't think of a way to solve MY problems."

But okay, everyone was coming from a different place. I certainly wasn't going to argue. Afterwards we had Family Night, ordering out pizza. Marielle played a home video from when Devin was a year old. In the video Devin was in the bathtub requesting various toys he'd thrown, and subsequently again threw, out of the tub. In another video Devin got a bath in the kitchen sink, "Dad" sat in the "trike" playing with him and the rubber duckie, I sang "Rubber Duckie" from Sesame Street, the doorbell unexpectedly rang and Jeff went to answer, sporting that determined-to-be-helpful-despite look and gestures that I remember so well. It was Arin at the door and Arin snapped at "Dad" because the trike had rammed into him. Marielle said, tearfully, "I had forgotten how Dad INTERACTED with us, playing with Devin and all." I answered, "I hadn't forgotten."

Arin hadn't been at the Inglis House memorial, nor was he at Family Night that evening. He'd skipped off to the Poconos, having had "enough", as he and I put it. Bret said he'd gotten a message from Arin saying, "I'm going through hard times but I love you." That night I dreamt that Arin asked. "Mom, would you send me a sympathy card?"

"Oh," I answered, "ya mean, 'cause Dad died?" "Yeah."

"Sure, Pokey. I'll send you a sympathy card." In the dream, I understood. Arin needed a sympathy care from *me* for at least two reasons: One, we weren't in the same bereavement; his loss wasn't the same as mine. Two, he needed extra mothering. As I was waking up I thought about what the sympathy card could say. "I'm so sorry for your loss, whatever it was. Please know that I love you and am with you, wherever you are."

In the Philadelphia Inquirer that day the main obituary was Jeff's. In 1984 he'd made the front page of that paper by solving a problem posed by Einstein. Now the obituary made long mention, again, of that solution; the paper had also gone into its database and found their review of "Dirty Details" so my book was mentioned too. Jeff had obituaries in several other papers, including one I put in the Well Spouse newsletter.

In January 2004 we found out that there had been no will-crap. I got half of Jeff's pension and the kids got the other half. Every one of the four kids asked me, "Mom, is that money supposed to be yours? Should I give it back to you?" "No," I had answered. "This is fine the way it is." In fact, I prefer it this way. The kids are financially independent. I don't have to think about "helping them out", like many parents of grown children. They're not independently wealthy, but they're independent, period. The same for me.

Jon and I set the date for August 8, 2004. My anniversary with Jeff was August 9 -- for similar reasons as Jon's and my August date: we wanted it later in the summer so there'd be lots of time, after my spring semester, to prepare -- in particular, for *me* to invade the thrift stores and flea markets for wedding paraphernalia -- dress ingredients, wedding decor... -- and to generally be happy and anticipatory -- but also not too late, meaning not too close to the start of my fall semester. Once I finished up the year at USP, I really went to town, or rather ABOUT town. I thrifted several times a week. I couldn't miss the bridal picture frames, in particular Lenox for a dollar, nor the bride and groom figurine. Nor, eventually, the flow-y silk nightgown, the bottom of which was perfect for the bottom of THE dress. Nor, shortly afterwards, the vintage lace slip, the top of which was perfect for the top. (The twain met perfectly.) The wedding would be in our

first loft-style floor; for food we'd arrange deliveries from places Vietnamese, Indonesian, Thai, and Indian. We would marry ourselves, Quaker-style (but not as Quakers), and the marriage would not be legal; we viewed it as being "under" neither God nor country. I made the summer of 2004 a childlike summer of play, a "summer of our content". For invitations I shopped in Chinatown for rice paper and selected something with browns, yellows, and a smattering of orange. On the front they say, "Jon and Marion would like to invite you to --" and on the inside " -- our wedding!"

Right now I'm sitting yards away from the "wedding museum". Yes, my favorite wedding paraphernalia are on the two shelves in this computer room. I'm looking at the multiple cake toppers, vintage artificial lilies, favorite vases brought by guests-- we'd requested white flowers in lieu of other presents. Then I turn around and see the 50's bride doll that Jon and I found on our San Francisco honeymoon. That's one advantage of a home wedding -- some of it lasts forever.

The day before the wedding was something to remember. Kathydeck had offered to come in the day before to help out, and such an "honor" had to be shared by Freda, my friend from 'way back. So they both arrived in the early afternoon of August 7. I was ready with six large bags of wedding goodies. We spilled it all out and began decorating. And laughing. We have photos of Kathy trying on one of the "spare wedding dresses", \$10 in Village Thrift. She looked amazing; I told her she could keep it and she did. Freda then said "Wait a minute -- I want a dress, too", and there was indeed one for her. We have pictures of the three of us on the big bed, giddy as all get-out. Jon and I took them out to dinner at that great pizza/pasta place a short block away.

At 1:00 PM wedding day I had on, not *the* dress, but the “greet-the-guests dress”. Yes, I’d made two dresses and couldn’t bring myself to choose. The greet-the-guests dress consisted of different white-based fabrics, each placed vertically. Jon’s greet-the-guests outfit was off-white shorts and a white with turquoise flowers Hawaiian shirt. For an hour the guests were arriving and we partied. At 1:45 Jon and I went upstairs to start getting dressed. Freda and Kathy followed us, to help with whatever was needed -- and to insist, as Jon and I went into the bedroom, “UH-UH! The bride and groom can’t see each other before the ceremony!” Jon and I laughingly complied.

Soon we were re-united at the top of the stairway. And I felt the wedding-ness. I had not expected that. I was happy at my wedding to Jeff but I don’t remember *that* happiness. Cathy, professional pianist, was downstairs playing The Wedding March. Jon and I walked down the “aisle”. The photos show him looking at me in a way that made some of my friends later say, “Marion, you don’t have anything to worry about”. I’m looking down, in ecstasy. savoring. I’m thinking, “This is a moment to last as long as possible.”

After us came the three “flower-children”, Cathy’s Stephi and my two grandsons. Jack was the ring bearer; proudly and regally he bore the white satin pillow in the middle of which sat the two rings. Stephi and Shane each carried a basket of tiny white flowers. The “altar” was in front of our large living room window. Freda and Cathy had suggested a rug there, and we chose a 5 x 7 off-white silk Oriental “prayer rug” dug out from one of the closets. As we stood at the “altar” I surveyed our guests. We’d bought plenty of white plastic “temporary” chairs at Rite Aid, but most people were sitting on the stairs. What a sight! Andrea, Susan, Barbara, Joe, and four well spouses: Fern, Rita, Dina, and

Marty. (Normie lived too far and couldn't get a ride.) Down on the floor, Kathy, my sister Rosalyn and her husband Bob, Marielle's Matt's parents, Freda looking almost as happy as I was, Jeana (my office mate at USP) with her husband, flea market friends Lois and Harry, Susan and Richard, my oldest friends of all (After returning from our honeymoon we received a gigantic email from them, containing 150 photos which they'd taken.), Lili Bitá (who later read, as she'd "warned" me, her very erotic and locally-famous poem), Phyllis (head of the Teaching/Learning Center at USP), Zoray from the Ethical Society, Jeff's old friend and colleague Phil and his wife Nancy (now that there was no possibility of their telling Jeff about Jon, they could be invited), my Brooklyn publisher Roberta, Jon's younger son Bryan (His older son was in the Czech Republic at the time.), and of course all four of my own children, in particular Marielle with the video camera, and my Muslim friend Maryam (I'd asked her whether she felt comfortable going to weddings, and she'd answered, "I'd love to come to YOUR wedding". In the photos she's laughing heartily at some of the jokes in our vows.). I never did count the guests; most of the 110 replies to our invitation had been yes's. The living room plus stairs were amply filled.

And so the ceremony began. First Jon and I hugged. Then I began: "Everybody here, and also those friends and loved ones who couldn't be here, thank you so much for being here, in actuality or in spirit -- for wanting to take part in our happiness and celebration. Last year we were celebrating our move-in and the beginning of live-in. Well, the year-plus of live-in has been 'successful', and we've felt very happy and complete. But we wanted to have a ceremony... And also -- gotta admit it -- I (Marion) wanted to wear

(and spend months shopping for) a really fancy white dress - and I (Jon) wanted all this food and that cake over there ... and both us wanted to give an especially big party.

“I want to tell you how happy I am and how much I love Jon. When I was looking on the internet, I had a lot of ‘druthers’. I wanted someone who was not only not a wacko but also mature (in particular, non-negative self-image so it wouldn’t translate into crap), leftist, someone who could understand my love and preoccupation with math, appreciate my writing, and tolerate my thrifting and home-schooling ideas. I also hoped for someone passionate about his work... and someone who’d be loving, happy to be in love, and emotionally available. And I needed someone who would be a Mensch about my being (at the time) a well spouse. A couple of my friends (Hi there, Susan and Andrea!) thought I was being too particular, but -- I actually found somebody, namely Jon, who is all of these things, and then some, like being six feet tall...” Laughter, supportive and hearty, propagated through to the back yard and to the second floor.

“Jon also possesses the necessary ingredient of pursuing what he wanted -- namely me! Jon courted me, loved me, treated me well, and committed to me. In time it also, happily, became clear that Jon is very easy to get along with. Since I also am easy to get along with (I think!), that makes for an unbelievably easy and blissful life. Twenty and a half months ago Jon changed feast to famine, bitterness to happiness, feelings of alienation to those of citizenship, and Murphy’s Laws to the regular laws of the human condition. For both of us this is a happiness hard won. I am so thrilled and proud today.”

Then Jon began reading what he had written the evening before and what had made me bask in happiness: “Meeting you was certainly the high point of my life so far, and

today will mark the beginning of the best part of my life. You are more beautiful, wise, kind, cheering, supporting, exciting, and mind-expanding than anyone I have ever met.

To reciprocate even slightly what you have done for me already, I promise to:

- 1) Support you with my suggestions, however misguided!
- 2) Not work to the point of neglecting you (a maximum of two all-nighters a year!)
-- More ripples, or rather waves, or laughter, which are very evident in our photos.
- 3) Attend all of your parties and some of your Scrabble games -- More laughter
- 4) Ask you out on dates, at least sometimes, before you get a chance to ask me
- 5) Never say "Aren't you shopping a bit TOO much?" -- smiles in my direction.
- 6) Supply you with just enough current events
- 7) Practice the Mozart sonata diligently -- so we can play it at the guitar party
- 8) Help Upstairs Babe with all her computer woes

--- "Yeah," I interrupted. "His computer's on the second floor and mine's on the third.

So, when we email, he's Downstairs Babe and I'm Upstairs Babe..." -- More laughter.

- 9) Never say or do anything to hurt you.
- 10) Love, cherish, and (mostly) obey you to the best of my ability, now and
for the rest of my life!"

I had slightly more vows than he had. Quantity is partly what I'm about! "Even though I don't usually think of weddings in terms of vows, I promise to..." Many of my vows corresponded to his. But some had to do with being a former well spouse. "I promise to:

- 8) love you until death (or anything worse than death, or anything that should be death) do us part -- as long as it's possible to -- as long as you don't abuse me --

as long as no ex-post-facto laws are passed.

9) NEVER abuse you

10) never say or do anything to hurt you

11) always recognize and soothe your wounds

12) If we ever reach an impasse in discussing any of our issues that might arise I promise to agree to go together to see a therapist -- in particular, if YOU should feel the need to see a therapist with me, to NOT REFUSE to. And finally:

13) be loving to you RIGHT NOW, all of today, DURING our wedding (not only for the rest of our lives) -- to not ignore you, not forget you in the midst of all the excitement.”

And now it was time. “Do you, Jon, promise to try your darnedest to keep your vows and in particular to love and cherish me for a very long time -- forever, if possible?”

“I do. And do you, Babe, promise to try your darnedest to keep your vows and in particular to love and cherish me for a very long time -- forever, if possible?”

I paused. It was just soooo delicious. “I -- do.”

“And SO” -- speaking together now -- “in the eyes of nature, beauty, absolute truth, the Buddha, and all sentient beings -- and most of all, ourselves -- we hereby pronounce us -- “ More pause. This was even more delicious. -- “MARRIED!!!”

The photo shows that pause, and it shows that final letting go. I’ve got my arms thrown out, in complete abandon, in an effort to hold -- Jon, the entire world, all of time.

“Hey, wait a sec!” called out several people. “What about the rings?!” Indeed. “Oh yeah...” The whole world was laughing. “Jack, will you please bring us the rings?” Jack. looking extremely solemn, walked on over with the ring pillow. Jon took my ring, I took

his, we put the rings on each other's fingers. The photos show it. I was thinking, "THIS is THE moment. The THE-est moment! This is REALLY the moment!" I've got my eyes closed, in ecstasy, in another attempt to make a moment last forever.

But letting go of that moment wasn't bad, either! "May I kiss the bride?" asked Jon. "Well, may I kiss the groom?" I countered. The various photos show that kiss and the ensuing hug from various angles. In some only my face peeks out, in some only Jon's. Then it was time to throw the bouquet. Kim caught it. In the photo she's looking sheepish and cute. "I DO have a blind date this weekend," she exclaimed. "Friends are fixing me up." "Oh, Kim!" I exclaimed back. "He'll be the one, I just know it." I then called attention to the huge basket of other thrift store bouquets. "For anybody who wants one... " Then "we would love it people would come up and say something." And so began the first round of toasts. My sister, Jeff's cousin Jana, Lili Bitá, her husband Robert, Freda, Kathydeck, and Marielle ("It's so nice to see my mom happy again.")

Then came the receiving line. I'd forgotten about receiving lines. Phil and Nancy proclaimed, "Second marriages are wonderful. We know." "We know, too," we answered. The line soon resolved into a PLANE, the whole floor of us "eating, drinking, and making merry." Jon and I stayed together most of the time, in keeping with my vow. An hour or so later was a second round of toasts. Lili read her erotic poem, the one that ends, "When I was a girl I believed that people could copulate ONCE -- only ONCE -- and DIE of the pleasure... Make me believe it AGAIN!". Barbara read a couple of poems. Phyllis sang a special song for us. And Andrea got up to tease me "Yep, I remember how particular you were. There was one guy you rejected because his emails were too short!"

The party lasted 'til 10:30. We had hired someone, a friend of a friend, to clean up afterwards so we didn't have to. After most of the guests had left, Dev's friend Jade arrived and the two of them began "jammin". It so happened that they jammed the horah. That's not usually what they jam, but this time they did. Perhaps they sensed I was in the mood, big-time, for it. The photos don't show that horah but I remember it well.

Freda and Kathydeck were sleeping over and a bunch of us sat around on the couch, still in "wedding mode" as Jon and I opened presents. The one I remember was the box of cards, from the Philadelphia Museum, called Kiss. Inside were cards with various arty kisses, but on the cover was simply the word KISS in large block letters. One photo shows us holding up that big KISS; a second photo shows us actually kissing! "Well," we quipped, "It SAYS 'KISS'."

Finally it was time to turn in. Freda and Kathy slept in the guest room, and Jon and I - well, we did make a big deal about it being our wedding-night. But not before putting on the wedding video that Marielle had made for us. Excitedly we awaited the watching of our wedding. But soon we realized that watching was all we'd be doing. For somehow the sound hadn't been working on the camera. So we watched. The next morning, before catching our plane, I phoned Marielle to say good-bye and make sure she had our contact info. I hoped she wouldn't ask how the video was but she did.. "Oh, that's horrible!" she exclaimed." That's just HORRIBLE." "Sweetie, it's not that bad," I told her.

"Oh, I see," she said, calming down. "You're just so happy that nothing matters."

"Right." We had purposely scheduled our flight to be not terribly early; the purpose of it all was to be happy, not rushed. But eventually Freda and Kathydeck drove off, and

Jon and I walked off to the station to catch the airport train. We had 50's "Just-Married" streamers on our suitcases. Somebody on a bike stopped and asked, with a smile, "Are you really just-married?" "Yep," we answered. "Congratulations!" he shouted.

I'll just say it was a wonderful honeymoon. I continued to have the special feeling. We went to museums, saw Shakespeare in the Park, watched movies, went to Japan Town, many fabulous restaurants, in particular a Korean one that gives you nine bowls of relishes (not four like most Korean places). We even went to several thrift stores. When I think of that honeymoon, I feel sad that it will never be again. But then I remember that every time Jon and I go on a trip together, there's a special feeling.

When we got back I emailed the Separation/Divorce group; the subject line was "Wedding Former Well Spouse Style". I also sent an announcement to the Well Spouse newsletter. In it I described Jon as a "Japanese translator, philosopher, classical guitarist, and generally fabulous guy who was completely cool and supportive during the final illness and dying of her ill spouse."

"Do you feel comfortable putting that in?" I asked Marty, the newsletter editor.

"Definitely," he emailed back. "That's exactly the kind of thing we're hoping for."

I sent Normie a "souvenir pack" -- wedding favors, vows, my poem, and one of the flea market vintage "bouquets". She phoned me the next day, ecstatic. "You sent me the wedding!" she exclaimed. "I couldn't get there so you sent it to me!"

And that's the happy ending of this book, or rather the happy middle. I'm still in this happy middle. I wish this middle could go on forever! I wish it could be the end!

CHAPTER XVIII: ONCE A WELL SPOUSE, ALWAYS A FORMER WELL SPOUSE

Middle or end, I'm a former well spouse. Once a well spouse, always a former well spouse. I'm not fighting it. But I'm WRESTLING with it. There is much that a former well spouse wrestles with. Well spouse friends Rita and Dina came to visit. We sat around my kitchen table and talked. They were still so happy for me, and incredulous that it's possible to be a spouse who's not a well spouse. "And he's healthy?" they asked.

"Yes," I answered. But I felt a trifle guilty that I wasn't, just then, telling them that Jon has Type II diabetes. It's truly no big deal. He is, after all, in his 60's (as am I) and can't be expected to be completely healthy. A former well spouse is not obligated to find a new partner in perfect health. Still, with Rita and Dina that day, I wanted to fit into the fantasy. I was not in the mood for qualifying my simple answer of "yes".

Another thing I wrestle with is a particular stereotype that some people persist in believing. They don't really have it right. Or they have it TOO right. Sometimes it gets back to me that "all she did during those years was take care of Jeff."

Not exactly. Not even approximately. What about the poems, the books, the teaching, the baby, home-schooling, thrifting, presenting at week-long conferences? "ALL she did was take care of Jeff." What's that about? Whose interests does that mindset serve?

Another thing I wrestle with is something I just realized the other day. During a meeting of our Scrabble group I started to talk about something from my writing life. Barbara

and Bonnie talk about their artist lives; Susan talks about her work life. But it seemed to me that they didn't want to devote a lot of time to mull over what I had to relate. I emailed Susan about that, asking her if perhaps that had only been my impression. But no, she'd noticed it too. "Perhaps it's because you don't have any real problems," she offered. "You're in a good relationship and..." We had other theories. So, later, did Jon and I. "Maybe people aren't that interested in writer problems." "Maybe people in general just aren't interested in other people's stuff."

While I was in the throes of well-spouse-ry, I'd often find myself the center of attention at parties. People knew my situation and cared or were fascinated. But I didn't want to be identified only as well spouse, and I wanted to hear what other people had to talk about, to simply be a partygoer. So I consciously tried to counteract that, not talk too much, steer the conversation towards others. I was also worried that a well-spouse conversation could get out of hand, take up too much time. Maybe that became a habit. Maybe sometimes it feels safest not to start things at all. And maybe, when I do start things, I unconsciously encourage people to not put much time into them.

Then there's the usual thing survivors wrestle with: post traumatic stress syndrome. My case feels mild. But the other day Dev, aged 21, asked me to put his clothes in the dryer once the washer was done; he had to leave for work. That evening Jon and I were relaxing with a video; suddenly I heard Dev downstairs. "Omigod," I said. "Omigod. I forgot. I just forgot. I'm a terrible mother. I'm self-centered, forgetful and..." What had me over the edge was, after work Dev would leave on a vacation; those wet clothes would have to be packed in his suitcase. Not the end of the world, but the end of my rope. Jon

gave me a look and I caught myself. But I don't think that "it" would be there to "get over" if I hadn't been through so much, once upon a rather recent time.

I've written a sequence of poems titled "The Life and Habits of the Child of Misfortune". I made a note: "These poems are about post traumatic stress syndrome, not depression." They have lines like "she has learned to thrive against the cold and thrives too much against the warm". Yes, I probably do "thrive too much against the warm". I'm no longer a "child of misfortune". I possess the Law of Averages. But I've had to unlearn a few things, re-learn my country, not "thrive too much".

I have survived much, but can I survive survival? What is the role of the survivor? How much post-traumatic stress syndrome is she allowed? How bitter may she be? And what is the role of the survivor who's a writer? What can/should she write about? Can she write on her past laurels? That's one reason my book of "math poems" was so important to me. It showed that I did not need to write on past laurels.

When I see someone in a wheelchair, especially if she has "that look", meaning the look Jeff had, I walk the other way. "Uh-oh." I think. "She's gonna ask me to help her with something." Cathy once said, "Well, you have a very kind face." And so I have a slightly shameful habit; when I see somebody in a wheelchair who's alone, I take off my kind face. -- Please, everybody, know that, when someone in a wheelchair does need help, I give it -- if it's possible and if it's not something like putting sunflower seeds in her mouth. And I do it with the expertise that I've unwillingly acquired.

As you've seen, I keep in touch with many well spouses and former well spouses. I've also made new well spouse friends, people I've since connected with because of

what we have in common. These are by no means the only friends I have, but I do sometimes wonder whether I tend to be attracted to people who are in some way down-trodden. I try very hard to wrestle with that tendency, whether or not it actually exists.

A little more than a year ago, I had another unexplainable experience, something that felt suspicious. I was hired to teach a course at UPenn. Things seemed to go well, as my classes usually do. True, there were adjustments I learned to make; UPenn is a different kind of school; its syllabi are very heavily loaded. But I was re-hired for a spring course. A month into it I got the teaching ratings from the fall course. As I sat on the bench just outside my classroom, I opened that envelope and the first phrase I read was “one of the best teachers I’ve ever had...” I smiled. It felt very familiar. But then I saw the beginning of that sentence. “The T.A. was...”

I know that students tend to think of T.A.’s as the heroes, the rescuers. They tell T.A.’s things like “the teacher never taught us that”. Now my T.A. was billed as hero and I as villain. I have never in my life gotten such ratings. “Can’t explain.” “Students walk all over her.” “Should never be teaching at Penn.” Nobody said anything good. Not the students who’d followed me from the Pre-Freshman program the summer before. Not the student whom I’d gone out of my way to help pass the course. Not the several who’d come to my office every Friday. Not the handful who’d written me complimentary emails. Not that half of the class who’d come to the evening session I’d taught specially so they could go home early for Thanksgiving. “That was very helpful,” many had told me.

I immediately emailed the chairperson. “This is very puzzling to me. Not only is it not at all my impression of the quality of my teaching; it’s not my impression of how THE

STUDENTS felt.” He emailed back. “It’s very puzzling to me, too.” “You know,” he told me later when we met in his office, “when I first hired you... you hadn’t been in here five minutes when I thought, ‘They’re gonna LOVE her’.” He seemed worried. “They go by the numbers... for some reason, the system failed you but I don’t know why.” Part of me thought, “I know why.” But the bigger part did *not* feel as though the laws of probability had been warped in my disfavor, did not feel exiled or framed up. Even after I got the letter saying, “We don’t have courses for you next year but would like to keep you in mind for future courses,” I simply felt puzzled, the way a regular citizen would.

Okay, so survivors of big things still have to survive little things. But the big things still hurt. What I went through, what Jeff went through. Sometimes I still hear that plaintive voice, “Mar. Please, Mar...”

The other day somebody asked me, not WHY did you do it for so long? but HOW did you do it for so long? I answered, “The way I was able to ‘do it for so long’ was by fighting it. By ‘doing it’ as little as possible, always with the thought of respite and end. I ‘did it’ by not going with the flow, not accepting it. Accepting would not, for me, have been wise. If I had accepted, I doubt I could have kept doing it.”

This is an era which I wish would go on forever. Or at least be the last era. Sometimes I feel that it’s lasting longer than I thought it would. I’m probably due for another bend in the road. I worry before doctor appointments. I’m in very good health and I think maybe I’ve been lucky in that respect for too long. Or maybe the powers *think* I’ve been too lucky too long. There I go again.

I think a lot about death. I'm afraid of death, and dying; I don't just-plain not want to die. I'm pretty impressionable at movies; I'm afraid I'll learn about some new type of torture. Also, I don't enjoy taking showers, the way many people do. I feel afraid in the shower, afraid of falling, breaking my spinal column, falling, paralyzed, to a "freak" position where my nose, both nostrils, is right in line with one of the jets of water. In the shower I think about water-boarding. Is all that because I'm a former well spouse or simply because I'm sensitive? I can't know. That's part of post traumatic stress syndrome -- the impossibility of knowing certain things about oneself because there have been too many variables. "The child-of-misfortune / can never be sure."

I'm thinking, now, of Devin's old Futuristic story, the one mentioned in the first chapter, the one ending, "It's still the end. Still the end." It's not still the end. In fact, it's still the middle. A person's life has many middles, but this is one of my better middles. I want it to be this middle for just a little longer. I would like it to be as chronic as those twenty-six years.

