

CRUEL AND UNUSUAL

Marion Deutsche Cohen

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WANTING OUT, GETTING OUT (about how sometimes, in particular sometimes eventually, the only real solution is to stop being a well spouse or at-home care giver. At-home care givers should not be discouraged from considering the idea. Well spouses and at-home care givers should be given the option and the opportunity, at various points in their odysseys, to re-evaluate the choice (if indeed if *was* a choice) to be a care giver, and to discontinue their services if they so choose. Society and its health care system should be supportive towards well spouses and care givers who are or have come to that point. At this moment in time, health-care workers should be as supportive and helpful as the present health care laws and policies allow, and the hope is that these laws and policies will change.

SUGGESTIONS FOR THOSE IN CHARGE (This is, in part, a “how-to” with respect to the last sentence in the description of the previous chapter. These are suggestions which can be implemented NOW, despite the fact that we might have to wait for generations for the health care laws to allow health care workers to perform their jobs in ways that are COMPLETELY humane.)

INTRODUCTION

This intro is meant to supplement my two care giving/well spouse memoirs (*Dirty Details: The Days and Nights of a Well Spouse*, and *Still the End: Memoir of a Nursing Home Wife*). Much of the content of this collection of essays can be found in those two memoirs -- however, not all of it, and not in a form that presents my beliefs in a coalesced form.

This intro summarizes the two memoirs. It tells the story of one well spouse, and provides the important background for what appears in this book.

In August of 1994 I was in an ecstatic state. I had been newly freed of certain “dirty details” of my life. These could be summarized as “the dirty details of care giving”. Sixteen years before my spouse Jeff, the father of our four children, had been diagnosed with multiple sclerosis. For the past six of those years he had been so disabled by the disease that he needed what is often referred to as “total care”. For all 128 hours of the week except the thirty provided by an agency (funded, so free to us), I was the one who provided that total care. Among other things, the physical realities of this care involved being awakened many times at night, to provide for his needs, lifting him (several tens of pounds heavier than me) to and from wheelchair, bed, and toilet.

At first this care was done out of love, and a certain kind of joy amidst our closeness with each other, our many activities together and apart, “my” math and writing, “his” physics and solar energy, “our” home-schooling, and so on, and especially the baby- and toddler-hood of our youngest child Devin. But after a while I felt, gradually and increasingly, frustrated, unappreciated, desperate, nervous, taken advantage of, and just plain desperate and tired.

“*Dirty Details: The Days and Nights of a Well Spouse*” describes those last six years. It describes the “dire straits” under which our family lived, the “nights, lifting, and toilet” that became our lives, the alienation that we felt from our world (despite so much help and support from friends), and the “conspiracy of silence” on the part of society, in particular the professionals in the health care system, when I told doctors, nurses, and social workers of our “dire straits”, and of my desire to stop living under such “dire straits”. The book also describes my eventual soul-searchings and conclusion that I neither could nor wanted to “do this” any more. These soul-searchings culminated in my insistence, in August of 1994, that Jeff live in a nursing home. August 19 was the important date. The last chapter of “*Dirty Details*” tries to describe and communicate, especially to those who haven’t experienced that kind of thing, why nursing home placement was so important, and why, even though I knew that Jeff was, of course, having a totally different experience, I was able to and allowed myself to feel a relief bordering on thrill, to be allowed to sleep at night, all night, and all the

subsequent nights -- and when awakened, awakened by children rather than husband, for glasses of water and nightmares. rather than by husband for itch-scratching, nose-wiping, toileting, turnovers, range of motion, ventilator adjusting, and so on.

In the morning, too, it was wonderful not to have to worry and/or wonder whether or not the home health aide would show and, in the evenings and weekends, it felt great not to have to *be* the home health aide. There was, in those August 1994 days, a strange, if sobering, excitement in knowing that I would never again have to do “nights, lifting, and toilet”, and that the entire family, though still living with a loss and though still including in our family my spouse whom we visited and phoned, was no longer in such “dire straits”, and no longer felt like second- or third-class citizens. In particular, the kids and I could indulge in small pleasures like going to a movie whenever we wanted, or playing an uninterrupted game of Scrabble. And little Devin and I could stay in the park past 4:00, along with the other parents and kids.

I did not miss having Jeff at home because I had already gone through the grieving process over the loss of him as an equal partner in our marriage. Besides, I was too relieved to miss him. Yes, there was, in those days, a strange excitement in possessing this new life.

In the summer of 1995 we had had almost a full year of this freedom; the ecstasy and gratitude were still in full bloom. In some sense it was even stronger because things were more settled; Jeff was acclimating to the nursing home and I had recovered from the “dire straits” that we had had to endure for so long. The “dirty details” still fresh in memory, but no longer in actuality, this was the perfect time to sit down and write my memoir “Dirty Details.”

From 6:30 to 9:00 every morning I stole down to my typewriter, set up in the kitchen away from my bedroom where Devin, the eight-year-old, still slept. Or else I stayed in the bedroom and quietly researched my diary of the last six years, as well as my three books, published and un-published, of “well spouse poetry”. In six weeks, the penultimate draft of “Dirty Details” was completed. In another month it had almost found a publisher. (“It’s too angry,” the almost-publisher eventually wrote. “And while the anger is definitely justified, we’re concerned how readers will react.”) In another month “Dirty Details” found its actual publisher (Temple University Press) and the ecstasy over being freed of the “dirty details” was enhanced by that publication, along with the public relations that followed -- the support, affirmation, and closure which I received from readers, audience members, most of the reviewers. friends, family, and many of Jeff’s caregivers at the nursing home.

Twenty years have since passed. Of course, that ecstasy eventually

tapered. After a while it began to feel more like the norm, waking up at night and knowing that I was permitted to just roll over and go back to sleep -- or stay awake and write, uninterrupted. But although that particular ecstasy is largely over, the gratefulness is still there. Specifically, I still adore nights. Nights are an adventure. Nights are mine. I still can't quite believe that I don't work nights (and that I don't work 24 hours a day).

When I turn in, or when I awaken at 2:00 A.M., I sometimes ask myself in delicious anticipation, "What will I do now? Read? Write? Math?" Roll over and go back to sleep? Enjoy insomnia, and the privilege of just lying there?

Also, as of eleven years, I have someONE to turn or awaken to, and he's not a child. That's one of the many great big changes in my life. The sequel memoir, *Still the End: Memoir of a Nursing Home Wife* describes them. Here is a summary of that sequel memoir:

My first husband Jeff was very very sick, living in a nursing home, chronically ill and often ACUTELY ill. There were certainly a phenomenal number -- an increasing number -- of "dirty details" for HIM -- 24 hours a day, 7 days a week, no respite. Except for very restricted, very slow, and very infrequent hand movements, he was completely paralyzed. He was soon on a feeding tube and his voice was very very weak, sometimes practically non-existent or actually non-existent. Moreover, his personality and judgment, if not his physics ability, was increasingly affected. There was never any doubt in my mind that his sufferings exceeded mine and our children's, and they greatly escalated until eventually chronic became acute. There was certainly no relief, ecstasy, and anything approaching normal life for HIM, and the empathy I felt for him often translated into upset, pensiveness, and brooding.

There were still some physical caregiving "dirty details" for me. I visited him twice a week at first, then, after years and the acquisition of a fulltime mathprof position, reduced the visits to once a week. During these visits I suctioned him, wiped his nose, cleaned his eyes, and negotiated in the hallways with three wheelchairs at a time (while simultaneously feeling extremely grateful that it was no longer I who did "nights, lifting, and toilet", also that it was not I in the wheelchair).

Being the "family member" of a nursing home resident often puts one in the same kind of "funny position" -- the same role -- as being an at-home caregiver. And that, for me, was hard, both personally and politically; personally, the similarities to at-home caregiving threatened to prevent me from moving on in my own life. Also, the fourth essay in this book, "Not Even Volunteers", describes how, in many ways "family members" of people in nursing homes are second-class citizens.

I am still angry about the “conspiracy of silence” described in “Dirty Details” -- the conspiracy, on the part of the health-care system and society, that allowed me -- and is still allowing and thereby effectively forcing at-home care givers -- to do “nights, lifting, and toilet” and to live in “dire straits,” for an indefinite amount of time. To a feminist and humanist, this seems metaphoric of many other wrongs that exist in this society. They can seem to border on a kind of ABUSE. (This is described in the second essay, “Epsilon Woman: Care giving as a Gender Issue”.)

There are many societal attitudes which I believe need changing. The tendency to glorify and/or spiritualize care giving, less than truthfully, still seems to prevail. For example, one article in a prominent caregiver newsletter is titled, “Inner Strength”. “70 per cent of care givers,” it reports enthusiastically, “found an inner strength they didn’t know they had.” To me that sounded as though they were implying that that “inner strength” somehow justifies the conditions under which at-home care givers are made to live their lives. I felt like retorting, “When you hear yourself saying ‘I never thought I’d find the strength to do this,’ maybe it’s time to start re-evaluating whether you SHOULD find the strength to do this.,” What care givers need more of, I wanted to continue, is OUTER strength -- meaning the strength of OTHER people. (This societal tendency to deify and exaggerate the power of “inner strength” is described in the chapter “Sugar-Coating and Other Non-Solutions”.)

In Still the End I tell how, as a nursing home wife, I experienced a NEW form of the “conspiracy of silence” mentioned above. My husband’s cognitive loss caused him to get paranoid about money (a common scenario with chronic illness and cognitive loss) and to threaten to withhold his disability and social security payments from my youngest son and me, and put the money in a special trust fund for him. I tried to prevent this. Knowing that his dementia was increasing, and that the doctors at the nursing home knew this, I spoke to them, and to other staff members at the nursing home, asking if something could be done; perhaps Jeff could be declared mentally incompetent, or at least incompetent in money matters. That’s when I got the “conspiracy of silence” treatment.

Mental incompetence is very difficult to prove, under the present law -- or rather, the definition of mental incompetence is so broad that essentially NO ONE is mentally incompetent. When I told the health care professionals of my plight, and uttered my plea, some staff members kept mum, some murmured “u-huh”, some made promises which, after the fact, I know they couldn’t keep, others were downright rude, as though I WERE the problem whereas in actuality I HAD the problem.

The health care system, and society in general, is in great denial about the true nature of cognitive loss, particularly when that loss is subtle. It insists on going by the stereotypical definition and by the standard competency tests. And because Jeff could say what day of the week it was, who the president was, and even talk physics (or at least what SOUNDS to non-physicists like physics), he was considered legally “competent”, and allowed to be financially abusive to his family.

I was not requesting that he be deprived of all rights, or declared a vegetable. I was only requesting that he be denied the right to make financial decisions which were harmful to my children and me. But under the present laws, there seems to be no middle ground; incompetent means vegetable, and it's either vegetable or meat. The kids and I lost out big-time (a common dementia catastrophe).

The title of this present book comes from the way I was feeling after a meeting of Jeff and me with a social worker at the nursing home. As is very common with people with cognitive loss, Jeff had accused me of stealing his money and had said that his intentions were to never let Devin and me have more than the minimal \$650 a month, nor sell the house which was far too big for just Devin and me to live in. Via eloquent speaking and dignified pleading I had, at this meeting, done all the work in convincing him to do better; the social worker had not said or done anything on that score. Mainly, that meeting had been very upsetting, for want of a better word, and I had needed comfort and deserved “strokes”. However, even AFTER Jeff had gone back to his room and the social worker and I were alone in her office, I received NO comfort, NO support, NO pats on the back, and NO help.

In the week following I had assessed my situation: I was in limbo, I could not divorce, I could not sell the house, I was (pun intended) on “house arrest”. But what really hurt was this: In not challenging the hurtful and uncalled-for things that Jeff had said, the system was effectively denying that Jeff had said those things. Along the same lines, in not declaring Jeff incompetent it was, virtually, declaring ME incompetent. When the system fails to convict a rapist, it is saying that the rape victim has not been raped; it is also convicting the rape victim of exaggerating, lying, imagining, and / or being a “slut”. (I was not and am not saying that I believe that rapists should be severely punished; I was saying that the rape, along with the rape victim, should be ACKNOWLEDGED, restitution made.)

It seemed to me that I was being dealt something cruel and unusual -- but cruel and unusual WHAT? Punishment? But I had committed no crime. I've never even shoplifted, nor smoked a cigarette of any kind. I had, in fact, been an upright citizen, above and beyond. For what would I be punished?

The conspiracy of silence is, or is tantamount to, cruel and unusual SOMETHING. Hence the title of this book.

I have still been concerned, not only about myself, but about ALL at-home care givers, especially since I keep in touch with many. One is no longer in love with her spouse/care receiver. But he still loves -- or needs -- her, and is continually "at" her. "Like a boyfriend you want to break up with," I remarked, "only he LIVES IN YOUR HOUSE." "Yes," she said. Another, because of the dynamics and conflicts involved, must leave, not only her spouse, but her children. More and more frequently, I see and come to know well spouses who do not WANT to be well spouses, who are trying to get out of it, somehow. And I see that this is very hard, next to impossible, to do, for practical if not emotional reasons. -- in particular, for societal reasons.

I have also been concerned that many care giver "support" groups and organizations seem to have the mindset that a care giver has chosen, and WILL (and should) CONTINUE TO CHOOSE, to be a care giver; I am concerned that change is not part of the picture. Several years ago, at a well spouse workshop someone handed out literature about an "adaptive device" that would allow a person in a wheelchair to do more things. My friend Rita was a little upset by this; "Forgive me if I'm offending anyone," she added, "but I DON'T WANT any equipment that will make it possible for my husband to live at home forever." (She looked towards me. "I read Marion's book," she said, 'and I don't want to ever have to go through THAT.")

In general, I have not found much in the care giver literature, or legislation, that incorporates much attitude concerning a care giver being given, truly, the choice to NOT be a care giver, and to me this seems to be an important goal. (Throughout this book, but especially in the essays "Wanting Out, Getting Out" and the last "Suggestions" chapter, I have tried to do my part in correcting this situation.)

After Jeff had been living in the nursing home for seven years, I realized that the marriage was over. I also realized that, if I did not separate myself from the situation, my physical and/or mental health would suffer. "Should I get a divorce?", I wondered. I had now reached the point where I wanted to, but it would be stressful and costly for both of us, and I would incur huge financial loss. Moreover, he could die shortly after the divorce became final, thus defeating the whole purpose. The situation was further complicated by the specter of Medicaid.)

I did "have a life" -- in particular, a new professional life, as a fulltime mathprof for four years, then a more serious adjunct math prof (in search of fulltime, which

I missed “by that much” several times at several institutions, because of budget cuts), and also as the author and presenter of “math poems”, reviewer of math books, and amateur at “actual math research”. I continued my “fun” life with thrift shopping and, with all my trials and tribs, strengthened old friendships and made several new ones. I was, emotionally and psychologically, in what is often called “a very good place”. And I realized that I needed to be making some personal decisions, which could involve some “dirty details” of a more typical kind.

So I began dating. For what seemed a very long time, I tried earnestly and determinedly (though not desperately) to find someone with whom I could get, and give, a second chance at happiness. Anyone who is or has ever been single and seeking knows what that’s like. Add to that the overwhelming odds against finding someone who would understand and be cool about my situation, and who was enough of a Mensch to stay with me and believe me when I said that I would divorce if I could . (This is also a common scenario, though not one which all well spouses choose, even eventually. The chapter “The Sex Workshop” goes into more detail about how and whether well spouses do anything about their emotional and sexual needs.)

My story has a happy ending. I actually met someone! (Yes, I, and some friends of mine, are living proof that, in time, the Onlines work!) Jon and I moved in together in July of 2003, before Jeff died several months later, and we plan to live happily ever after, for as long as “ever after” lasts.

Jeff’s dying was a very important milestone. As when he went to live in the nursing home, I was both relieved (for the both of us) and ecstatic (for me). If ever a death was “a blessing”, this was. I saw him on his last day; in fact, I was the last friend/family member to see him. His face was paralyzed, too. His eyes had had to be sutured half-shut, because they had kept popping open. His skin was apple-red everywhere. His stomach, heart, lungs, and brain had all stopped working. He had wanted to stick it out to the very end, and that was the kind of end that someone who has so chosen winds up with. I only hope that he was completely unconscious and not suffering. The staff at the hospital had been extremely frustrated at, legally, being prevented by Jeff’s advance directive, and by his two lawyer brothers, from pulling the plug or even giving morphine. In fact, at the time of his death they were in the process of contesting that Advance Directive, bringing the matter up before the Ethics Committee. (And this was a Catholic hospital.)

At the time of Jeff’s death a very important and very pertinent book was published, “Liberating Losses: When Death Brings Relief”, by Jennifer Elison, Ed. D. and Chris McGonigle, Ph.D Its release couldn’t have been more timely. It talks about “non-traditional reactions” to death, and “non-traditional grieverers” -- in particular, non-grieverers, period. It uses the phrase “chronically living”, and states,

“not all care giving is caring.”

If ever there was a non-traditional griever, I was. And if ever a loss was liberating, if ever a death was a release from burden, Jeff's was. It was, in short, a HAPPENING. I had ALREADY gone through the “chronic grief” described in “Dirty Details”, and through every OTHER kind of grief there is, including “anticipatory grief”. I had already reflected on our good early years, been overwhelmed by the sadness of the whole situation, been recurrently impressed with Jeff's physics accomplishments, felt increasing compassion for him, had already therapied myself into understanding what it all meant in terms of my own life (and death), and had come to truly believe in my heart of hearts that I wanted and deserved to “move on”. In short, I had processed and I was not grieving. I didn't really need that book, “Liberating Losses” but I read it, with pleasure, and I'm glad it's there for those who do need it.

In the following essays I hope I've emphasized these and other ideas more strongly than I have already. Now that you know my own story, as background, I hope to inform society of these ideas. And I hope to convince.

This is a tall order, and the thrust of this book is to do my part. It's a tall order, and I'm tall!

WHAT CARE GIVERS DO (CARE GIVING 101)

“Some of this is almost ancient history”, emails Sarah, a well spouse whom I know from the Well Spouse (online) Bulletin Board. “I will have to dig into my memory. . . . When we were dating, I loved his sense of humor. I loved how respectfully he treated me: opening doors, etc. He was (and still is) so proud of the fact that I am a nurse. I was so proud that he wanted to be a pastor. We met in college. We started dating while I was a junior and he was in graduate school (seminary study for ordained Lutheran ministry). We were engaged in July 1968, had our wedding planned for December 1969. We had a huge wedding, about 300 people. We were married at the college chapel where we went to college and where my dad taught for over forty years and where I worshipped while in high school because our church building burned down.

“He had been tentatively diagnosed [with multiple sclerosis] in May of ‘69. The literature at that time said that life expectancy was 20 years, death from kidney infections -- which by 1969 I knew we had antibiotics to treat. The literature also said over two thirds of M.S. people never progress to needing a wheelchair. So, as a senior nursing student I figured “no problem”.

Today, over three decades later, I ask her, “What, as a care giver, do you physically do?”

“How long a list!” begins her answer. “Start with bathing, dressing, positioning in bed. Transfer from bed to w/c [wheelchair], or w/c to anything else. Drive him to any/all medical appointments, and anywhere else. Decide when to buy a new vehicle, what to pay for it, and keep it maintained. Weekly I take him 80 miles one way to a place called the MS Achievement Center, which is essentially a day activity/therapy center for people with moderate to severe MS, including social and spiritual support, PT [physical therapy], OT [occupational therapy], therapeutic recreation for cognitive skills, and some family support. Arrange all medical care, administer all meds, fix all meals, modify texture secondary to chewing and swallowing issues. When he developed a blood clot in his lungs 20 years ago and needed to be on long term (6 months) of blood thinner, I drew his blood and took it to the clinic, as that was easier than transporting him to the clinic. For a year I did intermittent catheterizations, then for several years I changed his Foley catheter monthly. He now has a suprapubic catheter (through the abdomen), and although I am physically and professionally capable of changing that, I have drawn a line of refusal. I do take care of the catheter, emptying the bag, pushing fluids, identifying when a urine culture is needed for severe bacterial infection. I manage his bowel program, so that we rarely have incontinent BM’s any more. When he is too tired to eat, I feed him. I observe him for fatigue, and see to it that he gets the rest that he needs.

Of course, I do the menu planning, all the shopping, all the bill paying, buy all his clothes, maintain the house and yard. Sometimes I sit with him and watch a TV show so we can do something together. He is an only child; when his mother was a widow and as she was dying, then afterwards, I did what I could from 80 miles away to be supportive to her. He could not get into her house with 12 steps to get to the front door. And I cleaned out her house (on his behalf) after she died. I handle all the money, make all the investment decisions ... did I say that already? I read aloud to him parts of books that he might be interested in. See to it that he gets to church as often as possible. Play cribbage with him / deal the cards since he can't / and keep score, moving the pegs, etc. Don't play Scrabble any more as he can't put together a three-letter word for the game board. Oh, I forgot laundry. Major laundry!"

How well I (Marion Cohen) remember throwing in at least one set of bed-clothes a day, as well as last-minute clothing changes. What Sarah does, physically, as a caregiver will later become more apparent and dramatic as it comes up in response to other questions and conversations. For now, I move on and ask, "What do you do EMOTIONALLY as a care giver?"

"He has difficulty expressing himself. I help him identify what he is feeling, by giving him a list of multiple options and having him choose what is closest to his answer. He is unable to come up with the words for most of what he wants to say, so I am pretty much the keeper and "expresser" of his memories and emotions. When he was very angry about his illness progressing, he blamed me, as in the cycle of violence. He had no control over what was happening in his body so he tried to control me. Fortunately I understood what was happening because of my nursing knowledge of how people may react to disease, so I knew to blame the disease, not him. It still hurt to hear some of the things he said to me."

More about what she does for him emotionally will also come out later in answer to other questions that I asked. But for now: she goes on to talk about some of *her* emotions. "I grieve that this man who graduated magna cum laude from an excellent private liberal arts college has such severe cognitive deterioration. I grieve that he was unable to fulfill his dreams educationally and professionally. I grieve for myself and for him that our marriage has been celibate for probably over twenty years. I am also proud that I have been able to "endure" (I mean in the sense of stamina) for all these years, being faithful to my marriage vows. I get tired, overwhelmed, I wonder, with the Psalmist of Psalm 13: How long, O Lord, how long? I praise and thank God for my health, that I have been able to care for him this long. I hope for a future after his death with someone healthy. I worry that something might happen to my mother before my husband dies; then I would need to care for him by myself, as well as care for her. I was so romantically in love when we were married; love and marriage now is seen in terms of commitment, of self giving, of caring for another human being who is

totally incapable of doing for himself. He never even asks for food or drink, just eats what I put in front of him. I try not to worry about the future, but try to trust God for God's timing. I cannot hurry or slow his deterioration."

Sarah works half-time as a nurse in Obstetrics and Gynecology. "I would never survive if my paid job was caring for sick people and their families. It would be too much like home." She works evenings, 3:00 to 11:30 P.M., "so I don't have to worry about whether the aide will show up in the morning." Immediately I wondered what happens at night when she comes home. Does an aide also put him to bed or does she, Sarah, do that? "Yes, but my shift is done at 11:30, I rarely get out before 11:45, and usually it's after midnight. Then it's a half-hour drive home. So it's more than 1:00 when I get home. Then I wake him, and move him from the recliner to the w/c [wheelchair], and push him to the bedroom, transfer him to bed, get him positioned, empty the catheter bag, then get ready for bed myself, or go check my emails and then get to bed. That's why some of my letters [emails] are late. . ."

Sarah shared with me thoughts from her diary of some twenty years ago, when she was a care giver not only to her husband Rev. Andrew Johnson, but also to her spouse's mother who had a serious stomach disorder. "Andrew has said that he has a wonderful quality of life -- because of me: my love, my care, all the things I do for him. Maybe my [own] quality of life isn't what I would like, but 'be careful what you pray for, you might get it.' I know no other life. Jesus said, he who loses his life for my sake will find it. My life IS that of a caregiver. God doesn't call us to a life of eternal Seven-Flags amusement parts. God calls us to lives of service to one another. Yes, sometimes I whine about it, that it's 'unfair' that so much is asked of me. But I don't like myself when I am feeling 'whiney'. And there are only about two or three people in whom I confide when I am feeling that way. They just listen, tell me that it's okay to feel that way, that I am doing a great job, and that they honor what I am doing. And the despair passes. I think what is hard for me is that our culture, our society, does not value the same things I do. Someone once said we are, after all, called human beings, not human doings. However, we live as human doings, and love seems legitimate only when it is returned. Yes, Andrew loves me, but more like a child, not in the adult role of companion, husband, leader of the household. When I married him, I knew that I loved him enough to take care of him. I didn't have any idea what that meant at the time.

At a wedding last Friday, while the priest was talking, I was thinking: Being told that laying down one's life for another is great love, felt like such an affirmation! I am laying down my life for Andrew, and GOD HONORS THAT! Sometimes it is hard to pick out just the right gift for someone you love. You want them to be happy with the gift. God is happy with the gift I offer... the gift of being God's representative in caring for Andrew.

“Since I was four years old I have been on a straight path toward being a registered nurse. It is not my ‘chosen’ profession but the service to which I have been called. Jesus said, ‘Whatever you do to the least of these who are my brothers and sisters, you do to me.’ I care for Andrew and I know that I am serving Jesus. When I care for Andrew, I also know that it is Jesus who cares for him.”

Sarah seems extremely centered, and sure of the choices she has made. Lest we fit her into some stereotype, she tells me, “My expression of faith is not Polyanna, not an attempt to ignore the hard things. Far from it. And while it gets me through the hard times, there are certainly times of frustration and discouragement. Like today and yesterday, when I worked so hard to get halfway caught up on laundry, and there was just as much to do today. And all that paperwork. I am the kind of person who wants to do things well. And since I can’t do clutter-control well, or efficiently, I hate to do it. And it carries very few intrinsic rewards. Mostly the reverse. I guess it could be called intrinsic punishments, as I sit there trying to sort stuff and can’t figure out a filing system, scolding myself for letting it get out of hand... and on and on. And Andrew just sits there and sleeps in his chair. Every half-hour today I had to take time to tell him to drink (to keep the catheter working). He just didn’t seem interested. Yesterday he showed interest as I set up the CD player with great music. He was nicely awake and alert. Today every time I looked at him he head was drooping and he was asleep and drooling. I hate drool (and what it means).”

I’m reminded of another recent email from her: “Today is our son’s thirty-second birthday, in some ways a bittersweet day for me. Of course we love our son and I would be devastated if we had not had him. But I had wanted more children. Combine a low sperm count with prostatitis and impotence, add limited in bed mobility, and you have a recipe for long term celibacy, not pregnancy.”

And another email: ‘I had a delightful childhood but all I remember about adulthood is taking care of him. I’m tired of being my own husband; not having a partner to trust with any household responsibilities. It’s like being a widow (grief, lonely, responsible for everything, little active help with parenting) but with a husband so there is not freedom to date or seek a new relationship. I remember asking him to do something and he’ll say ‘I’ll try’. I learned what ‘I’ll try’ meant.”

In our emailing Sarah and I shared a lot of well-spouse LOL. “Once in a great while,” she once wrote, “he would put forth the effort to put away the dishes from the dishwasher. He would proudly say, ‘I put away YOUR dishes’. That always infuriated me and I always told him they were OUR dishes, that HE ate off them too. it never sank in until finally one day I said to him, firmly, ‘Look, if we ever get a divorce, even though these dishes were a wedding gift to both of us,

from both your friends and relatives as well as mine, I GET THEM! All our married life you've been calling them mine, so I will keep them!' He never called them 'your' dishes again. :) But he never put them away again, either. :(

One of her latest emails to me ends on a pure-friendly note: "Well, I'm not done with the table, but it's close. If I get some of the kitchen table also cleared off, I can move what's left in the DR to the kitchen and remove the tablecloth, shake out the dust, maybe put on a clean one, and get myself some flowers tomorrow."

"Nights, lifting, and toilet' are very much part of my life," writes a relatively new well spouse named Rick, after reading the chapter of that title in my memoir "Dirty Details". "Generally I'm pretty okay with it although sometimes I am very fearful about the long view of our situation."

56 years old and married for just six years when his wife had a very severe aneurysm three years ago, Rick still loves her very much, and he tells me, "happy. . . sometimes I am." He has written down their story. "In 1991 I was divorced after 21 years of marriage and two children. After about four years I met an angel named Marnie. From the day I met her, I knew that I would marry her despite the fact that there were plenty of ladies in my life at that time. Marnie had been described as having the eyes of a doe and NEVER had a bad thing to say about anyone. She was a seamstress with her own business out of her modest townhouse and gave up a career as a fashion designer after her ugly divorce, to raise her three children all by herself. [She] was well educated with a year as a sociology major and then later earning a degree at the Fashion Institute of Technology in New York. As a child she grew up under the influence of a strong family of teachers and artists. Her father was a long time design professor at Buffalo State College and her mom was both a homemaker and an art teacher. Her brother was a ceramic artist in New York and her sister was a professor of Early Childhood Education. In 1961 Marnie's father established an exchange program for art students at Buffalo State to study art in Siena Italy, and Marnie and her family lived in Siena for a couple of years, and later travelled back there frequently. Thus Siena, art, Europe, teaching, sewing, her children, and her unpleasant divorce had a large influence on her gentle soul.

"I met her through friends and we dated, danced, travelled and married in 1995. We really enjoyed our lives. On August 11, 2001 we attended the Fergus Scottish Festival in Fergus Ontario; when we returned from the festival back to the B & B, we prepared to retire for the night and shortly after midnight, as Marnie and I were talking about the day's activities in bed, I realized that I'd forgotten to take my heart medication. I got up to do so and when I returned, I found Marnie unconscious with her eyes rolled back and muttering something that I couldn't

understand. I thought she was just kidding around but realized soon after that something was wrong.

“I held her in my arms and her body was totally flaccid. I realized that she was not breathing at all and was convinced that she had passed. I began kissing her and weeping when it occurred to me that I might try breathing into her mouth to try to resuscitate her. This worked and she began to breath with difficulty and after several seconds the breathing stopped again. I repeated the resuscitation attempts and she began to breath again. Because I was afraid to leave her, I wondered how I was going to get help. I left her on the bed for a moment and pounded on the wall to the adjacent room and cried out for help. Luckily the room next door was occupied and the people came over. I ran to my car to get my cell phone and called 911. The police answered and said that an EMT would call back. They did, I explained the situation, and they arrived within about ten minutes.”

“At the time,” writes Rick in a more recent email, “I was really happy that I did what I did. I saved the life of a wonderful woman. Little did I realize that I just imposed a life sentence on her, me, and many others who know and love her.”

In the hospital the preliminary (and correct) diagnosis was a cerebral aneurysm. At the hospital that she was flown to, they told him that she was in grave condition and not expected to survive. Rick writes a five- page account of her “progress” over the next two-and-a-half years -- surgeries, fevers, infections, aneurysm clipping, plenty of rehab, weaning off the respirator, weaning off the trach tube, spasticity in her right shoulder, a prolonged grand mall seizure, a drug-induced coma and finally home four and a half months later. At this point Rick noted her accomplishments: “She continued to gain strength. She could sing common songs.”

Before Marnie could go home, the house needed to be modified: Ramp from kitchen to family room, ramp from family room to garage, electric stair lift, widening of the bathroom door upstairs, and a whirlpool bath for her comfort, and arrangements to resume PT, OT, and ST at an outpatient Rehab Department. “The plan was that I would drive her to ECM for a three-hour session three times per week. I tried this for two weeks and found it very difficult and not appropriate at the time for Marnie, so I found that I could get these three therapists coming to our home.” And of course, since Rick has a fulltime job, an aide. Several more pages in several emails describe their lives in the years since then. There have been three more hospitalizations, but none in the last sixteen months.

So, as a caregiver, what does Rick do? “A typical weekend day: get up before Marnie, do the dishes, do the laundry, feed the cats, clean their litter, take care of all kinds of routine stuff, then get Marnie up -- that is, swing her legs out

of bed, bend her forward and stand her up, pivot turn and hold her up while I 'untape' her soiled disposable briefs, pull them down, all while raising her night-gown up (seems like I have three hands but I don't), sit her on a commode and hope that she urinates within the time it takes to do the next things.

"Marnie cannot have a bowel movement on her own. After trying every laxative known to man, I concluded that the only thing that works is a good old fashioned Fleet enema. So every other day I administer one and it usually works well. Next things are, get a can of Boost Plus, collect up her pills, and give her her boost while putting her pills in her mouth one at a time. Then get the toothbrush, toothpaste, and a glass of water as well as one of those hospital 'spit troughs' so she can rinse and spit. If I don't put the trough under her mouth right away, she just spits as if it were there -- more cleanup.

"I sometimes take her in the shower with me, which really is heavy lifting as I sort of drag her into the stall and sit her on a shower seat. Getting her up and out is a little tougher in that she's wet and slippery. No accidents yet, but it's pretty hard on the old back. If I don't give her a shower, I wash her in bed, rolling her over from side to side to get all of her clean. I then lift her out of bed and on to a transport chair, then lift her from the chair to the stair lift, then from the stair lift to the wheelchair -- lots of lifting.

"Nights are pretty okay in that there are no machines to trip or other distractions. Usually I'm so tired that if anything non-urgent happens I sleep through it. I have a Fisher Price bed rail tucked between the mattress and box springs that acts as a safety rail so that Marnie doesn't fall out of bed. (She did once, and broke her hip.) When Marnie has to go to the bathroom during the night (usually twice) she drops the rail down and it goes 'thud' against the side of the bed. Like Pavlov's dog I know what that means so I reluctantly get up and put her on. She sometimes goes, sometimes not. It pisses me off when she can't go after all the trouble I went through. Remember, Marnie doesn't speak so it is speculation at best that prompts me to do things that I 'think' she needs."

"Let me tell you about aphasia," Rick begins his next email. "A person's communication center is in the left frontal lobe of the brain so, if that part is damaged, it is not only speech but general communications that are affected. You can have 'global aphasia' which means that you cannot receive OR express communications of any kind. Or you can have either one or the other -- receptive or expressive. At first Marnie had global but now it's 'only' expressive. However, that means that not only can't she speak; she can't communicate in any other ways such as writing or sign language. It's a lousy thing to have.

"With aphasia 'yes' doesn't always mean yes and 'no' doesn't always mean

no. I might say to her 'do you like ice cream?' and she'd say 'yes', and if I ask her 'Do you hate ice cream?' -- same answer, 'yes'. Marnie can complete common phrases but not necessarily using logic. For example, I might say 'the farmer in the - - -' and she'd say 'dell'. However, if I said 'I want to go. . .' she might say SOMETHING but it wouldn't necessarily make sense. . . You can't have much of a conversation with an aphasic person and if you're the well spouse, you'd better really like the sound of your voice because you're gonna hear a lot of it.

"The worst thing about aphasia is the frustration that it brings to Marnie and the potentially serious consequences of not being able to determine what she needs, how she feels, if something is wrong, etc. So I take the cautious route; if it appears that she's in pain, I try to get her to point to where it hurts and, knowing how she reacts to pain, I try to guess how serious it might be. Usually we wind up at the doctor's office or in the emergency room, where the same questioning starts, 'Where does it hurt? On a scale of 1 to 10...' I just tell them, give her every test that you can and maybe we'll find out.'

"About a month ago she was doubled up in abdominal pain. I tried to guess what the problem was but could not, so I took her to the ER and it turned out that she had BOTH kidney stones AND gall stones. Thank God they were able to find them. So it's constant guessing game for the care giver to try to figure out what the aphasic person wants and needs, not to mention that there's nobody around for you to talk to, plus the heart-wrenching frustration that you feel for the aphasic. Couple aphasia with the fact that Marnie suffered eyesight damage and you really have a guessing game on your hands. Marnie sees double, cannot cast her eyes up or down, and has a 'blind' spot in her upper right quadrant, all of which cannot be fixed."

Rick ends that email with "enough for now."

"I do nights, lifting, all bowel and urine care," writes Donna, "I do daily bathing and dressing. I lift him in and out of bed. I dress and undress him in bed. He can get to the washbasin and take care of his upper body. I take care of his lower body."

Donna Morton (not her real name), living somewhere in California, has been a well spouse since 1972, when her husband was diagnosed with multiple sclerosis. I know her through the Well Spouse Association, a national organization founded in 1988 by Maggie Strong, through the publication of her book, MAINSTAY. Donna and I see each other about once a year, at the annual Well Spouse weekend conferences; in between Octobers, we sometimes correspond. Donna has grown children, who for the most part don't want to know "what care

givers do." A son "can't" do any of what care givers do; it "makes him sick," Donna says. When he does, "he does it for his Dad, not for me. I wish he would do something for me." Or, if Donna calls in an emergency, "he comes over, does what needs to be done, and leaves." No understanding, no compassion or tenderness for his mother.

"I treat the toenails, bandage the scrapes, wait for the cellulitis, decubitis on his heels, put on the lambswool heel cups and inflatable hooks, change urine day and night bags, do digital stimulation [short for stimulation] bowel care every morning in bed and clean it up. I clean his backside with soap and water, baby oil, grease well with vaseline or Bag Balm, and re-diaper. I watch for bedsores and all irritations. I report everything to the Home Health nurse. I can be held accountable for everything that happens to him and his care."

Several years ago, when Donna retired early from the secretarial job she had held long enough to retire from, she at first contemplated trying something new and exciting. Pursuing a nursing degree had been her first thought. Then she reconsidered -- "had a brain alert," as she puts it. "If I got medical training, then I would be expected to do more medical skilled care for him. Now I can say 'I can't / don't know how to do that. I am not a nurse.' Yes, Donna, along with many well spouses, is very careful about pursuing dreams.

"There are questionable areas of when he falls do I pick him up or call 911. They get tired of coming here. I always ask him if he is hurt or does he want me to pick him up or call 911. Does he think anything is broken? Does he hurt? No, just pick me up! One time he went over backwards in his wheelchair and there was blood on the floor under his head. A 911 call. They... put him in a neckbrace and on a board, velcroed him down, then on a gurney, and transported by ambulance to the hospital. I followed in the van. The ER personnell looked at his head, said it was a superficial wound. They asked why he had come in by ambulance...", as though the fault were hers.

Damned if a care giver does and damned if she doesn't. And no mention or criticism, once he's disappeared, of the 911 guy who (incorrectly) determined that he needed to go to the hospital. All eyes and ears are on the ever-visible every-present care giver. "if you're innocent, what are you doing in court?"

Of course, caregivers also do all the things NON-care givers do -- alone. In Donna's case, "keep the household going, groceries, cooking, laundry" -- and all these things are harder when "the household" includes a chronically ill person -- that is, when "the household" resembles a hospital or nursing home. "Keep cars repaired, make ... decisions, cope with your own depression, and HIS. Try to make a life for yourself.... STIFF UPPER LIP, BE THERE, BE RESPONSIBLE... work the business of it,

and call it a war, and in the end we lose."

Yes, not a losing battle but a losing WAR. Such is CHRONIC illness, and CHRONIC care giving. Caregivers do and do and do. If there is an end in sight, this end is not in the CAREGIVER'S sight. During the seven years that I was an at-home heavy-duty caregiver, I believed, in particular I believed in my gut, that that period of my life would never end. I had no idea of the mechanics of things like nursing-home placement, or end-of-life issues. More about that in the essay, "Is it nursing-home time yet?"

"Tell me about stress," I asked her and she answered, "I asked my husband if he had or felt any stress. He said no. Why should they have stress? We (the care givers) have all the stress. Everything is done for the patient. They sit / lie there and take and take and take."

"Do you feel abused?" I asked. "Yes," she answered, " in its own form it is abuse. I am tired of them telling me that I have choices. The other choices are unacceptable."

"Do you feel as though you're in dire straits?" I couldn't help asking, using my own phrase for what I went through for over six years.. "No," Donna answered, "not yet." What's missing? I wonder. And then I think maybe I know: She doesn't have young children in the house (Her children are grown.), nor does she get waken up 30 times a night. Not yet. She has, though not 100% guaranteed, her nights off.

Donna writes me about love for him, as well as relations with friends. "Yes, I love him. Sometimes I get tired of him, the care he needs, the repetition... I get tired of trying to be upbeat all the time. ... I get tired of talking about his illness,... of repeating the story, ... of people asking me how he is. He is fine. I am not. I get tired of people telling me that I am such a good person, a good wife, have so much patience. I really want to scream at them, 'relieve me of all this.' "

I ask if humor ever truly helps. "Humor is mostly dark, jaded, sarcastic, a bit bitter... [and] mostly with my well spouse friends. The medical profession wants to know about his bowel movements. I say, 'What do you want to know? Quality? Quantity? Consistency? Color?' They don't think it is funny. I told one person I would throw some of it against the wall and see if it stuck or it it ran. She thought I was a very angry person."

Donna runs a well spouse support group. Although it's something she needs and values, it's also another demand on her. "The few support the many," she says, twice. "We are all caregivers and none of us have that much time."

"Are you coming to the conference this coming October?" I ask, one year. "Yes," she writes back. "Stan says not to worry, he will take care of getting help for himself. I want him to spend a week in a nursing-rest home. He is not too happy with that idea. Denial! He thinks he can take more care of himself than he really can... Other people tell me to go off and leave him and let him find out the hard way. [But] what will people say if something awful happens?..."

And now let's hear from a care giver who ISN'T missing what Donna's missing -- that is, a care giver who doesn't get nights off. From the article "A Good Night's Sleep" (Pat Kaufman, TAKE CARE, summer'95): Pat Corder is a widow, works full time, and cares for her 24-year-old son Tracy, who was paralyzed in a spinal cord injury. "Tracy has muscle spasms during the night," she notes. "They cause him to wake and often put him in rather uncomfortable positions. He has to call me to come move him and this happens at least once a night, sometimes two or three times."

The combination of interrupted sleep, waking up each day at 5:30 to get Tracy dressed and ready before she leaves for work, then coming home after 6:00 to make dinner and help Tracy with his physical therapy has left Corder, in a word, EXHAUSTED. "What I've seen," she says, "is a real inability to deal with problems when I get too tired. I know my worries here at home and at work won't go away just because I get more sleep, but at least when I'm rested, I'm able to cope better with them."

"The question is, given the fact that your care giving duties may be exactly the reason you've run up a debilitating sleep debt, what can you do to combat the problem of sleep deprivation? ...Studies have shown that the primary reason older parents are put into nursing homes is that their own disturbed sleep patterns have so disrupted the sleep of their care giving children that the children feel they have no other alternative but to institutionalize their parents. When you consider this reality, you can see that sleep deprivation is not just destructive on a personal level, but on a societal level as well." (Note: I would NOT agree that "institutionalizing" one's parents is destructive. However, I do agree with the conclusion that sleep deprivation, as well as other atrocities imposed upon care givers, is destructive on a societal level.)"

The article goes on to make various suggestions. "Educate yourself... just realizing that not getting enough sleep can lead to so many debilitating consequences will make you more open to finding ways to improve your sleep patterns." "Realize that medical professionals are rarely trained to identify sleep

problems." (Nor, I might add, caregiver problems in general) "Try to identify the source of your problem and make changes." "Consider hiring a home care aide to sleep over once or twice during the week." "If money is tight, this may be the time to call a family meeting and ask for help from others." "Talk to your priest or rabbi..." "Is it possible to get your care recipient out of the house during the day, to an adult day care center, or even for a drive with a neighbor, just to give you time for a cat nap?"

One more unusual solution was offered. "Julie... spoke to the manager of a local hotel, told him about her problem, and convinced him to allow her to use an empty room for a few hours one afternoon -- free of charge. She left work early that day and had a good long nap..."

The article never does say what happened to Pat Corder, how she managed to solve "her" sleep problem, who she found to share night duty with her for her 24-year-old son, whether she ever called a family meeting, and whether that made any difference, whether her priest or rabbi was able to find help for her, whether she was able to find a neighbor to take her son for a drive. During my seven dire straits years, the family meeting I called didn't make much difference, despite my following up on my requests for help. And I phoned every church and synagogue in town and was told, "Oh, we don't have THOSE kinds of volunteers." My guess is that Corder's problem was NOT solved. I make that guess because MOST caregivers' sleep problems aren't solved..

In my own six-year experience with sleep deprivation due to care giving, I tried every one of the "solutions" mentioned in that article. All were quite temporary. I "realized" the reality of sleep deprivation, I tried to educate my husband's doctors about it, I instituted changes that only partially worked (and my husband had MULTIPLE reasons for night-waking, not only spasms), the home health aides (and friends) whom we hired at night either burned out or, over the years, could not stay often enough for my well being and, again, neither church nor synagogue came through for our family. Also, getting sleep during the day was usually not an option since, among other things, I had a toddler son. Besides, I possibly would still have found myself wanting and needing to sleep AT NIGHT.

Indeed, if there were true solutions or even satisfactory partial solutions to the sleep deprivation problem, then there would possibly be solutions to ALL care giving problems. If society had reached the stage where "what care givers do" -- as well as what many care givers are not PERMITTED to do, such as sleep -- were recognized, then I would not have to have written the memoirs that I wrote, nor be writing this book.

The other thing that Donna doesn't have to contend with is young kids in the

house. Although I know from personal experience that kids can provide joy, as well as an escape from loneliness, in the midst of dire straits, there is still the question, What about the kids THEMSELVES? How are they doing?

The Well Spouse Foundation has identified the phenomenon of "well kids," the sons and daughter of chronically ill people. And during the past years an offshoot, Silver Lining, has developed -- a project designed to recognize and try to help "well kids" and their parents. Literature, support groups, outreach to professionals, policy makers, and ultimately legislators -- all are important to helping create the right societal mindset and enough resources. They won't completely solve society's problems, but they have helped, and it's nice to know that somebody cares.

Well kids have a lot on their shoulders. Even if not called upon to help with caregiving (and it's a much-debated question, how much help, emotionally and psychologically, is it "good" to call upon, or allow, kids to do), they have given up much of the innocence that is characteristic of childhood. They probably also feel a heightened feeling of responsibility, even if not actually GIVEN heightened responsibility. They have experienced, to various degrees and in various forms depending upon the particular situation, a distortion in family setup and dynamics, and in the roles they are expected to or want to play. At a time when identification with peer group is very important, they feel different, at least in that one way, from other kids their age. And while sometimes they might feel proud, even privileged, to have a parent or parents who have perhaps truly proven themselves as human beings and as parents, there are still also, at least at various "ages and stages", feelings of self-consciousness and embarrassment normal for those ages and stages. In some, or many, extreme cases kids have of necessity even been neglected; in "Mainstay" Maggie Strong describes how she was less likely to take her kids to the doctor when various slight symptoms appeared; there just wasn't the time or the energy. Also, kids in general tend to feel that they are the CAUSE of any illness or death in their lives, often because of the normal secret desires that kids have, in moments of normal anger or frustration, for that person to be sick, or dead. So well kids contend with some deep dark monsters. There are many other psychological issues, possibly the most prevalent being that well kids whose ill parent is of the same gender are at great risk in the self-image department, especially as pertains to empowerment, or loss or lack of. So another thing that caregivers with children do is contend, to various degrees of success and failure, with all those conditions and issues.

So another thing that caregivers do is worry. About the kids, and about everything else -- for example, bare-bones physical survival. In particular, finances. Both well spouses and ill spouses often make little or no money. They are limited in her earning power, because they are given less time, energy, and

resources than other citizens. Moreover, any help with caregiving costs money -- a LOT of money. Families are not businesses; they cannot usually afford to hire workers on a full-, or even part-, time basis. Insurance normally does not pay for "custodial care" ("Long-term care" insurance is very expensive; most families cannot afford it, and I've learned from the experiences of well spouses that I know, that it's quite limited in its scope). And a night lasts eight hours; to get a full night's sleep would therefore cost a caregiver eight times whatever the hourly night rate is. But the real financial worries begin once the illness has (often inevitably) reached the nursing home point, when the ill spouse must live in a nursing home and the nursing home must be paid for. If the (rare) family has enough money to pay the thousands per month, that money is often relatively quickly used up. At that point the family (now with no savings) joins the majority of families on Medicaid.

This is not the time or place, or even the book, to go into details about Medicaid. (The last chapter will give some ideas and suggestions on that front.) But Medicaid, even with the relatively recent changes, often involves at least some degree of impoverishment, indignity, and -- again -- worry. An anonymous well spouse writes a bit sarcastically about her plight and anguish: "I am allowed to make \$500 a month, before I have to start giving my earnings to the nursing home. The Medicaid office kindly suggested if I got a job at Wawa or something for less than 20 hours a week to keep myself busy, then I did not have to give any money back. The State just three years ago spent over \$5000 to pay for my retraining because I was a 'displaced' worker, and that office [now] wants to know whether I got a job or did they waste taxpayers money? The more I complain, the more I draw attention to my 'underground' finances. . . I can't earn social security wages for my future retirement, can't start building a new IRA. . . I have recently found myself in a real Catch 22 situation. . . When my husband first had his stroke, I evaluated my financial situation, transferred most of our assets to my name. I figured I had about five years worth of savings to allow me to stay home and take care of him and our daughter (she was 11 at the time). I never at that point thought he would live that long. I worked part time, went to school and eventually realized that I was running out of money, was mentally and physically exhausted. Finally I started to apply for Medicaid in order to get him placed in a nursing home. I found out that my IRA, which was the only significant asset we had left, was considered half his and had to be liquidated (spent down) before he could qualify for Medicaid. This had disastrous tax consequences, because I am under 59. . . I was still optimistic; I got a job, started making some money and slowly caught up with my bills. Now I just found out, Medicaid evaluates us once a year and if I make any more than a few hundred dollars a month, they start taking away my spousal allowance. . . . I have been condemned to mediocre poverty as long as my husband lives. He is doing so well in the nursing home, he'll probably outlive me... I don't know if it is worth it going to work. My daughter is planning to move out in the spring, which will cut

down my spousal allowance next year. I love my house, but don't have funds for the required maintenance and six years not keeping up is starting to show... I feel I have become a second-class citizen, the kind who should modestly lower my head, live quietly and thriftily. Maybe people like me should not live in nice homes, own a car or take vacations. Should I be satisfied with my lot? But why am I being punished for my husband having a stroke and with the advanced medical science saving him? I am angry that I am not allowed to improve myself, get a paying job, work hard and pay my debts... Maybe I'll find a low paying part-time job I am not overqualified for; McDonald's is out of the question; I just can't stand on my feet all day any more... I do have a good lawyer friend whom I can call for advice, but even friends cost money if they actually do some work on my behalf."

Will this woman's life ever get straightened out? Perhaps, after the passing of a fair amount of time. And energy. And youth, and life in general. And worry.

Another thing that caregivers do is feel, or begin to feel, lonely. The moment your spouse is diagnosed with a chronic (meaning forever, "til death do you part") disease, a kind of "anticipatory" separation between the two of you begins to take form and, though it might feel slight at first, or might be compensated for by the feeling of togetherness that sharing big news can bring (devastating, unreal, and temporary as it is), the fact is that each of you will be treading separate (if close together in distance) paths. "We probably spend more time with our spouses than almost any other couples do," says an anonymous writer in "The Forum" on loneliness, from Mainstay, the Well Spouse newsletter. "Yet," s/he continues, "we feel so lonely so much of the time. I think of me -- doing everything by myself -- married for 23 years, but all alone. Marriage wasn't meant to be this way."

In the same column, another well spouse ruminates, "I wonder sometimes whether he ever really cared about me or was it just my imagination? It pains me to live with someone who has no concerns for me aside from what might directly impact on him. Thank God for my job my co-workers and clients might never know the depths of my despair, but at least they affirm my existence as an individual, not just an appendage." And yet another: "Loneliness wakes me in the morning and puts me to bed at night. I live with loneliness all day... it hurts. Loneliness is all I find when I look around for my mate."

Well spouses have come up with many remedies for loneliness; get a job, get a friend, get a dog, get a hobby, get a lover, get a sense of yourself, get a vacation, get another well spouse as a friend. All help, often to a large extent, at least for awhile, depending on the individual, and on individual circumstances.

But if what one is lonely FOR is a real marriage, then none of the above is a real solution, and there remains the question: What to do? One contributor to the column poignantly describes the eventual bottom line here: "Last night my wife of 29 years and I had harsh words. She said she felt like a prisoner in her own home and no one cared. I responded by asking, 'How do you think I feel?' We talked it out as we usually do, but I came to realize we both have feelings which are opposite sides of the same coin. We both feel trapped and we both feel loneliness and we both know there isn't a damn thing we can do about it."

"I fantasize," writes another contributor to the column, "about the future when he's in a nursing home or dead and I can find a loving, nourishing mate who has the same interests as I do. Fantasy is my escape, which I leave for the dark hours of night."

Another thing that caregivers do is feel non-normal. Other. Second-, or third-, class citizens. Alienated. Just not quite in step with the world. One well spouse writes, "I keep hearing at work ~TGIF' (Thank Goodness it's Friday.). I've gotten to the point where I hate weekends because then I am home with my IS [ill spouse] full time. No excuse to. . . leave for a few hours to go to work. . . God, I hate my life." Yes, and weekends are when the home health aides don't come; weekends are what free services seem to pretend don't exist. And the END of weekends is the time for many at-home caregivers to exclaim "TGIM"! (Thank Goodness it's Monday.)

One final thing that some (though not all) caregivers do is wish they were NOT caregivers. Some even ask the health care system whether there might be a way out, and the agents of that system often (though not always; it depends.) shrug and display what, in Dirty Details, I called "the conspiracy of silence", One well spouse says, "Someone once made the point that the longer you wait, the harder it is to leave. I'm afraid I have waited too long already." "There were times along the way that I could have left," emails another caregiver named Kara, "such as when my ill spouse was in the hospital; I could have refused to bring him home, but it would have been VERY difficult and the hospital would have used major pressure and threats to try to get me to bring him home. When he was home, I couldn't get any help at all, even when I was supposed to be on bedrest when I had pneumonia and when I broke my ribs. No one was concerned about MY health. But if I had refused to care for him. . . they would have been out for me. . . I was screaming for help to everyone that I knew to ask -- social service agencies, government agencies, elected officials. . . no one seemed to care. . . but when my ill spouse and his family decided to make up allegations to ~get me' and HE said that he wanted to leave. . . all of a sudden, help has come out of the woodwork for him. And NO ONE expects his parents to do anything for him." Yes, another thing that caregivers do is try to live in a world and a system which, in

Kara's words, is "really mixed up."

SUGAR-COATING AND NON-SOLUTIONS (WELL SPOUSE 102)

Sometimes some things are horrible. Untenable. Calling, not for advice, not for words of encouragement, not for pep-talk, but for introspection, acknowledgement, self-expression, maybe screaming for a while – maybe even choices and changes. These last two are what make the acknowledgement of “untenable” , and the end of pure sugar-coating, worth it.

Indeed, there seem to be certain oft-repeated words, phrases, and sentences which people, including professionals and other well spouses, offer and which, often, mask as support but in truth can be enraging, because they do not accurately or completely describe the “untenable-ness” of the situation, much less provide solutions or even near-solutions. Instead, they carry over into societal attitudes, policies, and legislation (or lack of), thus propagating the mindset that there really is no problem. They pose a real threat and only worsen the problem. It’s important to identify and analyze sugar-coating mechanisms and non-solutions, beyond the more common ones such as “It’s for the best” and “God never asks more of us than we are capable of giving.” Here is a partial listing:

1) The word “stress”: It’s often not the correct word but a sugar-coating word. “It’s very sanitized,” says Dr. Suzanne Brennan, nurse and family therapist specializing in chronic illness. “Dire straits” is the phrase I personally prefer.

“Stress” is much softer than “dire straits”, “horror,” “craziness”, or other words I have heard actual well spouses use. Stress is when you begin a new job, new relationship, new baby. Stress, for me, was the first ten years between Jeff’s diagnosis and loss of ability to transfer. Stress is manageable without outside physical help.

“Dire straits”, on the other hand, is being awakened by the care recipient ten, twenty times a night for needs which may not be ignored. “Horror” is being alone in the house with someone who weighs more than you and who can’t move. “Craziness” is when that person spasms and falls to the (slippery) floor, or when, in addition, you, the care giver, have a cast on a broken ankle.

Calling these kinds of things “stress” might serve to make things sound, at least for the moment, better or simpler or possible, and it allows us to think in terms of “stress MANAGEMENT” rather than of rescue or other action. In other words, like other sugar-coaters, the word “stress” helps to keep up appearances; it’s an ENABLER. Calling dire straits “stress” can also feel insulting, even mocking or sadistic. “Stress” is an understatement and an undermining. “Stress” can feel weird and alienating.

In a similar vein, the word “difficult”, when we really mean “impossible”, has the same detrimental consequences.

2) Over-emphasis on the words “humor” and “happiness”: Well spouse meetings are full of well spouse “in-joking” and laughter. So was my own household during those seven years. With cats and kids jumping in and out of the bedpan, how could it be otherwise? Humor can be very helpful, enjoyable, and therapeutic, and can put things into perspective, might even spur one into action.

But humor by itself is not the solution. Humor does not make things tenable. When well spouses talk about their situations to acquaintances and to health-care professionals, they should perhaps be very careful not to put in too much humor; for fear of being misunderstood – for fear that people will get the idea that “it can’t be THAT bad.” It CAN be that bad.

There’s a difference between laughing out of happiness and laughing out of resignation or familiarity. (As I say in “Dirty Details,” “A sense of humor is not a sense of happiness. Laughing makes us happy only when we already ARE happy, and laughing without happiness can feel like a nightmare. Or like the laughter of losers.”)

As for “happy”, that word has been used to create many a sugar-coater and non-solution. “Don’t worry, be happy.” “You can be happy if you really want to be.” “Don’t lose sight of your inner happiness.” Our culture seems to be consumed with a kind of happiness mania; we seem to be afraid to let go of happiness -- or the appearance of happiness - for even a second.

Throughout the “dire straits” years, I was indeed a very happy person. I possessed the above-mentioned “inner happiness” brought on by my love for my family and work, and my sense of fun and joy; I also possessed “outer happiness” brought on by the recent birth of Jeff’s and my youngest child. One can be happy and in dire straits at the same time. But happiness, again, is not a solution. In particular, being urged to be happiER than we already are or can muster, without the basic problem being addressed, is the very opposite of a solution. The word “happiness” in the wrong context can hold us back from finding a REAL solution, as well as place blame on those who aren’t “happy” – that is, blame the victim.

3) Like “inner happiness,” the phrase “inner strength” can feel pretty suspicious to a caregiver, or to anyone who realizes that, lately, too many people have been complimenting her on her “inner strength.” A recent survey of the National Family Caregivers Association found that 70%... “found an inner strength they didn’t know they had.” This was reported in the care giver

newsletter, TAKE CARE, as a GOOD thing, the implication seeming to be that the “inner strength” found is somehow a justification of the “dire-straits” care-giving situations that many people are in.

Yes, as we live, caregivers and others do find inner strength. But that is not a solution to our problem. Also, the discovery of “inner strength” is subject to the law of diminishing returns.

Did we not possess enough inner strength BEFORE? Now that we do have enough inner strength, how much MORE do or will we need to acquire? Do non-caregivers not have inner strength? Are they exempt from acquiring it?

Some caregivers believe that this is what God wants them to do. This is not the place to discuss whether they’re right, or whether there’s a God. But what’s known for sure is: This is what SOCIETY wants them to do. In Stephen Hawking’s ex-wife Jane’s book, “Music to Move the Stars”, she relates that a friend of the family said to her, “You are as important to God as Stephen is.”

Inner strength (real, imagined, or exaggerated) is not a solution to the care giver problem. And if we find ourselves dipping into too much “inner strength,” perhaps it’s time to consider making changes.

4) Over-emphasis on the fact that ‘life lessons’ can and often are learned from these dire straits: Although that can be true at times in some cases, this is a variant on “inner strength”. ANYTHING that happens in life will, we hope, carry over and translate into “life lessons” (especially if the person living that life is a Mensch). I have learned many “life lessons’ from the happy things in my life, things which have nothing to do with being a well spouse.

Still, I have to admit that I sometimes wonder what poems and books I’d have written, and put time and energy into placing with publishers, if I had NOT had the well spouse experience. More baby poems? More feminist motherhood or home-schooling stuff? More math poems? Actual math research? What “life lessons”, and what creativity and accomplishments, did I NOT gain in exchange for those I did?

No doubt slaves, war veterans, and holocaust survivors learned many “life lessons”. But is learning “life lessons” a compensation or a justification for the ruining of life itself? Perhaps, when we begin to learn too many “life lessons”, that’s an indication that things have gone too far.

“I haven’t learned ANYTHING from care giving,” says Rita, well spouse and mother of two now-grown kids, both of whom had to delve and sift through far too many variables, in order to find their places in the world and in their family. “I’ve

never felt ANYTHING positive about it. It just ruined my life, that's all."

The poet Yeats seems to agree. "Too long a sacrifice / can make a stone of the heart."

5) Tellingly frequent reference to and reminders (often moralistic) of "those marriage vows": In my own experience, I always assumed 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." Back in 1964 I got married because I was in love. That was the extent of it. The ritual was meaningful because I was marrying Jeff; the words of that ceremony meant little or nothing to me, not with their literal meaning. Moreover, those words were not MY words. (This was before the days when it became more popular for couples to write their own ceremonies, as Jon and I did; neither Jeff and I, nor Jon and I, vowed to do care giving.)

And my feeling, if I had stopped to analyze, was that in order to marry Jeff I had to say "I do" to the whole package. I knew that I loved Jeff, expected to continue to love him, and would stand by him and be committed as long as that feeling remained, and as best I could. I never agreed to "nights, lifting, and toilet" -- nor to signing my life away, nor the lives of other people, in particular our children (and children do sometimes get neglected in the crossfire of care giving activity).

Also, like everybody else, care givers are allowed to change their minds, to DISavow. The divorce laws SAY so. One well spouse says half-jokingly that she thinks "all marriage vows should be re-written. For instance: "In sickness and in health" should be "in sickness will be hell"... "Til death do us part" might read "'til medical interventions do us part." "For richer or poorer" could be "'til spend-down has us repleted". "I take thee ..." could be "I take thee 'til I don't know who the hell you are any more"... and "I do" could be shamelessly changed to "I don't."

Seriously, no vow, marriage or otherwise, means anything over the passage of time, if it is not periodically and consciously reviewed and renewed, and if it not entered into with informed consent.

6) Another telling-ly over-deified word is "responsibility": Of course, a sense of responsibility is an important thing to have. But "responsibility" means responsibility towards EVERYONE, not only towards the care recipient. We have responsibilities towards our children, our family outside the household, our friends, our students, our colleagues, our clients, our customers, our readers, and our selves, which includes our persons as well as our work, our beliefs, and our values.

To plunge headlong and pervasively only or even mostly into our “responsibilities” towards the care recipient, and to neglect our responsibilities towards the rest of the world seems, to me, irresponsible (not to mention masochistic).

This ties back into “vows”; there are other vows in life, spoken and unspoken, besides the vow of marriage -- namely, vows made to people in our lives OTHER than our spouses / care receivers. For example, a new mother vows never to neglect her baby. Sisters or best friends vow to always find time for each other. A doctor, teacher, or other working or creative person vows to serve humankind to the best of her ability. These vows are also important and if, on any one occasion or in general, they conflict with our spousal vows, something has to give -- and that something might very well, at least on some occasions, be the ill spouse. In other words, speaking with perspective: In keeping to marriage vows, we might need to be careful not to neglect our other vows.

7) “It’s not him I’m angry at; it’s the disease.” That could be true; it’s often been true in my own case. But suppose it IS him. Suppose it’s NOT the disease. Would we have less permission to be angry?

Somehow it seems to be harder for many people to admit and accept anger against a person than against a disease. But in fact, anger at the care recipient is often justified. “The ill person is still held ACCOUNTABLE,” says Dr. Suzanne Brennan. “The care recipient has responsibilities, too.”

Indeed, no one is perfect; why should we expect the care recipient to be? In fact, whatever faults or shortcomings she or he had before the illness probably carried over into the illness, and eventually magnified. In particular, abusive spouses stay abusive (often just as dangerous, even if in different ways) if they become ill or disabled. I know many well spouses who report, along with progressive disease, progressive stubbornness, progressive paranoia, and so on. Other well spouses have talked about their ill spouses’ already existing and now escalating self-centered-ness and demanding-ness. So anger at a care recipient might very well be directed correctly towards him or her, and not always towards the disease.

“Many well spouses,” says psychologist and former well spouse Dr. Linda Welsh in her book “Chronic Illness and the Family,” “rationalize that it’s the illness and pain causing the behavior and it cannot be controlled. But many times it CAN be controlled. Anger and pain can be discussed rather than acted out.”

“Fairness in a relationship,” says Dr. Brennan, “is mandatory, EVEN IN THE FACE OF ILLNESS.”

8) Another tellingly oft-repeated statement is “I love him -- not the way he is NOW but the way he USED TO BE.” Yes, there is that element – occurring in different quantities and qualities, depending -- but—

“No I don’t! Not really!” vehemently admitted Norma, whose husband had had a stroke six years before and lived in a nursing home most of that time. There had been much dementia, much grieving, and much loving of the way he used to be, and “I’m FINISHED with all that,” she told me, slowly and emphatically. “Now I’m just ready for it all to be over.”

9) The term “loved one”: it seems to be used almost indiscriminately by care givers, health-care professionals, and hospital and nursing home literature. Somehow, when caregivers have feelings of guilt or embarrassment about “putting” a care recipient in a nursing home, or even temporarily in a hospital, that term “loved one” seems to provide some justification. Somehow the turning over to others the care of the care receiver is easier, or in our society appears less “cruel”, if that care recipient is referred to as a “loved one.”

True, the term can help show respect and reverence by professionals for the love felt for the care recipient by his or her family and, in times of hardship, it can provide a welcome perspective. But only if the care recipient actually IS a “loved one.”

And not all care recipients are. There are many reasons, other than love, that people become and/ or remain caregivers. For example, feelings of responsibility or obligation, embarrassment (in the face of relatives who might say, “You’re not going to put her in a nursing home, are you?”), guilt, financial necessity (or perceptions of), as well as simply getting roped into it and not knowing how to get out of it. (“There’s no one else to do it,” caregivers often say, and the health-care system doesn’t seem to help much in that regard.)

Even in cases where the care recipient IS in fact a “loved one”, the emotion of love is not always at the forefront -- in particular, when the stage of hospital or nursing home has been reached. Rather, emotions such as anger, frustration, worry, and confusion have taken reign.

Like most sugar-coaters, the phrase “loved one” can generate deep-seated guilt. “How come I don’t feel it that way?” can be the bottom-line reaction. It seems presumptuous for professionals to assume that care recipient X is a “loved one.” Just plain “care recipient” or “patient” would, I believe, be a better term. Caregivers can add on “love” when and if we choose.

10) Praising care givers: Sometimes praise can feel genuinely good; other times it feels like the pedestal that some men put women on, or like the flattery

that gets us nowhere. “You’re a strong woman.” “You’re doing great.” “You’re doing a wonderful job. KEEP IT UP.”

No thanks! There comes a time, or maybe there always WAS a time, when what is called for is not praise but change. Imagine telling a slave on the plantation, “Gee, you’re just sooooo good at picking cotton; we’re going to increase your hours!”

Unfortunately, that seems to be the mindset of some caregiving literature and support groups. “Don’t worry; WE know you’re doing your job.” “Don’t doubt yourself. You’re doing the right thing.” “You’ve made the right decision [to be a care giver].”

Praise can also be hypocritical. How do we KNOW whether or not a caregiver is “doing a great job”, when we have not gone into her home, in particular her bathroom during toileting time, to observe? Indeed, maybe we HAVEN’T made the right decision. Or maybe that decision was right at the time it was first made, but isn’t right any more.

11) Sometimes the very phrase “caregiving” seems like a sugar-coater. It’s a little like “springtime”, 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; how could something so innocent provoke such frustration, such desperation, such fatigue, such anger, such complaining?

But of course, the SOUND of a phrase and its meaning can be two very different things, and the term “caregiving” might be a misnomer. Many well spouses don’t like the term “caregiving”. It implies we give. Like calling being mugged purse giving, or calling being murdered life giving, or calling being raped sex giving. Perhaps “care VICTIM” would be a better and more honest word than “caregiver”. Or perhaps we should be paid and called “care SELLERS”? (Allow me, please, the luxury of counter-sugar-coating. Like sugar-coating, it’s okay to do SOMETIMES.)

When care givers reject sugar-coating, when they counter-sugarcoat , or when they react angrily and vehemently to sugar-coating, people often call it “complaining”, and/or they call the caregivers “selfish”. But statements like “This is ridiculous. This is impossible. This is unacceptable.” are often universal statements, not only personal ones. We’re not complaining only for ourselves, but for EVERYONE IN OUR SITUATION.

Complaining often leads to, or is, a political stance. Most social change starts with complaining. Centuries ago the writer and sometimes-feminist John Stuart Mill said, “Dissent is the prelude to revolution.” I would add, “And com-

plaining is the prelude to dissent.” Moreover, sugar-coating isn’t. Sugar-coating HOLDS BACK dissent, and change.

The history of complaining is extensive and impressive. Slaves have complained, blacks have complained, women have complained, workers have complained; if oppressed people didn’t ever complain, they’d stay oppressed. When a caregiver complains or tantrums, she is not asking “Why me?” Rather, she’s asking “Why US?” Meaning, why ALL care givers? Why EVERYBODY?

Complaining is the very OPPOSITE of selfish. It’s sugar-coating that can, effectively, be selfish because it deflects the expressions of the real problem and the real need, thus holding back any real solutions, for anybody.

As for “selfish”, the history of selfish-ness is also extensive and impressive, for similar reasons. Perhaps if we think of the word with a hyphen -- “self-ish” -- meaning having a self and valuing that self -- the entire matter might seem clearer. And it is by recognizing and honoring our own selves that we come to recognize and honor the selves of others, including the selves of care receivers.

To firm up: sugar-coating, if well used and well directed, can be beneficial. So can first-approximation solutions, if not disguised as EXACT solutions; they can help us get through hard times, help us feel better, even if only temporarily; they can help us move through the various (though, again, temporary) stages of grief, towards acceptance. Yes, sugar-coating and approximate solutions have their rightful place in the grieving process, or in any process. They can even help us cry, as we realize how untrue our sugar-coating statements are, how wishful our thinking.

But too often sugar-coating is NOT well used or well directed. Too often it’s used as the FINAL stage in a process, in place of acceptance, or in place of one of the other four stages, such as depression and bargaining, It can be something to get stuck on. It can give us, and others, PERMISSION to ignore the problem, and any solution or even partial- solution.

Indeed, care giving, for all its recent visibility in the media and in politics, remains a vastly under-described phenomenon, more so because of sugar-coating and non-answers. This is probably both the cause and the result of the way our health-care system operates. Because our policy-makers don’t know nor inquire, not on any great level, what caregiving really entails, they tend to come up with non-answers such as what passes for “respite care.” All too often, “respite care” means a mere few hours every six months. Or there’s some other catch, usually financial cost, or time expenditure, or some regulation. This makes the situation even more untenable and indescribable. While enough “respite care” would certainly be helpful, I would hate to see it become so hyped up that it hides

the need for real answers.

Many non-answers come in the form of non-advice. "Get out every once in a while." "Don't be afraid to cry." "Don't expect too much of yourself." "Make a list." Friends and health-care workers who give these pieces of advice only WISH those were real answers. But instead they put the responsibility -- and sometimes the blame -- on the victim. And again, these non-answers deflect from the real problem, and seem to be based on stereotypes and assumptions.

Even a caregiver cannot always know what another care giver's life is like. For example, at Well Spouse meetings and conferences I was often advised, "Go sleep in another room." But, with the form Jeff's illness took, that was the whole point; he had to have someone in the room with him at all times. The problem was not (as with some other caregiving situations) that his moving around, or coughing, or moaning, kept me awake; indeed I slept quite soundly until a very distinct voice called out "Mar," aimed specifically at me, for me to DO something. If I had slept in another room, I would have had to get OUT OF BED AND WALK AROUND in order to answer that voice, and to satisfy that voice's needs. To deny the reality of the problem is to deny the person who has the problem.

There are answers and there are answers. Some answers are more useful than others. Some answers are more honest than others. Some answers are more complicated than others. And so it goes. Such is life, and such is the ending of life.

NOT EVEN VOLUNTEERS: THE STATUS OF FAMILY MEMBERS

“One of the positives,” says Rick, “about Marnie’s tragedy (from Chapter I, a severe aneurism, which includes aphasia), “is that I personally met incredibly helpful and kind people. People with a capacity for compassion that I never knew existed in human beings.”

He relates two anecdotes. “When Marnie was to go to a nursing home, I found out that there was an excellent acute rehab program at a local public hospital. I asked the discharge planner and the PA about Marnie being able to participate in this Inpatient program and they nearly laughed at me. ‘No, she would have to be able to tolerate three hours of ST, OT, PT each day and there’s no way she could do it.’ I asked for an evaluation anyway and an angel appeared in the guise of a psychiatrist; her name is Doris Kelley. She spent about thirty minutes with Marnie. In truth, Marnie was pretty unresponsive and I was preparing for the worst -- a nursing home. Dr. Kelly finished her evaluation and I timidly came back into the room. She said ‘Of course she qualifies for the acute rehab program.’ She called in the discharge planner and we began arranging for Marnie’s transfer, not to a nursing home but to Rehab!!! I asked Dr. Kelley if I could hug her, she said OK, I did so, wept and moved forward, another obstacle out of the way due to wonderful intervention of a new angel in our lives...”

Rick also will never forget “a particular aide at Erie County Medical Center in Buffalo... There was an excellent whirlpool bathtub on the rehab floor at ECMC. Once a week this aide, whom I will call Esther, used to reserve the whirlpool tub for Marnie and me to enjoy all by ourselves. Privacy is not common in hospitals but Esther understood how important it was for Marnie and me to have some semi-intimate alone time. It was Christmas time, I took a radio and tape player in with me and we listened to Christmas music while I bathed Marnie. Although she was pretty ‘out of it’ at the time, there was always a smile on her face when she was in that whirlpool tub.”

Rick summarizes the whole scenario beautifully. “I love aides, they love us, they are absolutely unique people. For less than ten bucks an hour this is what they do: clean vomit, feces, urine, other things that come out of sick people; lift 300-pound people to the toilet; roll their clients from side to side; wash them, brush their teeth; use a variety of devices.”

Rick was also lucky to find two truly amazingly wonderful HOME health aides (very difficult to do, according to just about every other well spouse I’ve spoken with, and certainly according to my own past experience). “Judy has been with us for three years now and is truly a part of our family. She truly loves Marnie and we love her. She does normal aide duties but FAR exceeds expect-

ations in the love, caring, and compassion department. She provides hugs and kisses to Marnie as well as humor and meaningful activities. She communicates with her, takes her places and genuinely loves her. Judy is a treasure that, I understand, is hard to find... We are lucky to have another wonderful aide, Christine, who came along later and takes over when Judy's shift ends. Christine, like Judy, is very soft-spoken and very caring. Both Judy and Christine bring different things to Marnie's lives. Christine always leaves the house looking good. That is an enormous help to me both from a standpoint of me not having to do it as well as the satisfaction of coming home to a clean house. She ALWAYS kisses her lovingly when she is leaving. Two more angels in our lives. . ."

Although my own family was not quite as lucky as Rick's, we also eventually found two (out of something in the neighborhood of a hundred which, for various reasons, usually having to do with their soon pulling more "no-shows" than shows, just didn't work out) home health aides, described in "Dirty Details". I would also use the word "angel" to describe them. And once we got to the nursing home stage, the number of angels increased many-fold. I have always been extremely grateful that there are such things as nursing homes, along with people who qualify (in particular, as human beings) to work in them. And, as someone who had been an AT HOME caregiver for a long time, I not only appreciated but IDENTIFIED with the aides who attended to Jeff. I would always do my best to let the aides know this, and sometimes we had humorous exchanges (exchanges that were appropriate, given the fact that the care receiver was right there). There was, in many cases, a camaraderie. And although we all (or most) realized that there were also differences in our roles -- for example, they were paid, they went home at the end of the day (or the beginning, depending on the hours of their shifts), and they had professional status -- we stayed in touch about the things that were the same -- namely, we were all human beings doing the best we could in the face of certain realities.

However, also as a consequence of the human condition, there were also a few subtleties. With some aides, on some days, there was a kind of territorial competition between two people who were both caregivers to the same person and, by extension, to a large portion of the world. There were "attitudes", agendas, and power trips. For example, I felt insulted and sometimes saddened when some of the aides wouldn't "let" me stay in the room while they were tending to my husband. And, with the "higher-ups" -- for example, social workers and administrators -- I sometimes felt a mere lip service to my own dignity, and there were incidents which made me feel very low on the totem pole.

Several years ago the Family Member Support Group at Inglis House: a Wheelchair Community (where my husband lived) made an interesting proposal to the Board of Directors. Between the lines, this proposal says a lot about the

status of family members and significant others; here it is:

Proposal for Family Member Recognition Event

At Inglis House, as at many other skilled care facilities, there have often been special scheduled events -- luncheons, dinners, dances, and the like -- to honor the nurses, the volunteers, the administrators, and so on. We would like to propose a similar event to honor the family members, close friends, and "significant others" of our residents.

These are the people who brought our residents to Inglis House in the first place, and these are the ones who took care of them BEFORE they lived at Inglis House, who perhaps struggled to KEEP taking care of them and NOT have to bring them to Inglis House. In many cases these family members and significant others did the same things for them that Inglis House does not-- dressing, feeding, catheterizing, toileting, cleaning, medicine-managing, Hoyer-lifting (or bare-arm lifting), night-turning every two hours, and so on. Often, in a home setting, these logistics were next to impossible and we led daily heroic lives. We usually did all this unrecognized, unaided, and unpaid. we were often perceived by doctors and other health-care professionals as meddlesome and unknowledgable; we were advised, taught, and sometimes talked down to, when in fact we were also experts; we were the ones who'd been doing it for hours and years on end.

All of us 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. Some of us WERE the above-mentioned young children; as we were growing up, we gave up a lot -- some of our parents' attention, our innocence (in the form of more reality than most kids see), and some of our own free time, as we helped with the care giving, or with more chores than more kids do. We have all struggled with myriad and sometimes conflicting emotions -- love, disgust, frustration, resentment, anger, worry, fear, confusion, tenderness, despair, and fatigue. Making the decision to have our residents live at Inglis House was not always easy. (Implementing that decision was also not easy.) Many of us tried hard to keep our family member or significant other at home, but lack of equipment, adequate help, and finances eventually made that impossible. We have had to make emotional adjustments when our residents first came to Inglis House, and we are still adjusting; it's hard to relinquish responsibility and control, and to re-define our roles in life and our relationships with our residents, and 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 that Inglis House will

extend this caring and understanding, and use this “testimonial event” to increase our visibility and change our image even further.

There are several points which, again between the lines, that proposal seems to make:

1) That there had NOT previously been a family member recognition event says something about the status in our society of family members. (I have heard of only one skilled care facility which held such an event.)

2) Ditto the fact that the Board of Directors never acknowledged, let alone accepted, that proposal.

3) In fact, with the eventual resignation of one facilitator and death of the other, ended also the Family Member Support Group itself. The Inglis House administrators didn't find replacements. We understand the problems involved, but this does say something about the priorities; again, we're low on the totem pole.

Here, in some detail, are some of the duties performed by family members and significant others of nursing home residents:

1) Visiting: For many, this means every day, for the rest of our lives. Frail old women, sometimes themselves having disabilities or illnesses, take two or three buses, summers and winters, to and from. It takes hours; sometimes it takes the entire day. Most of these people seem so used to it, or feel that their troubles are nothing compared to that of the daughter, son, or other family member whom they're visiting, so they don't complain. (Even during the meetings of the Family Member Support Group there wasn't much complaining, mostly talk about concern for their ill relatives and the kind of care they were getting.) I did hear a hint of resentment in something said by one very small white-haired partially-deaf old woman with a 45-year-old daughter who had advanced multiple sclerosis. “I had a baby before her but that baby died. Now my only daughter turns out to have M. S.”

Visiting takes its emotional toll. The person we're visiting is often unhappy, uncomfortable, frustrated, and she sometimes complains about the aides. We feel a responsibility; should we have a talk with the social worker? the head nurse? go straight to the director? perhaps we need to find another facility for this person to live in? Perhaps we should let the person come back home? Etc. Of course, experience has taught us that there's little or nothing that we or anybody can do, but we still try.

Chronically ill people are very often -- understandably -- self-absorbed, complaining, demanding, paranoid, even bordering on abusive (especially if they were abusive BEFORE the illness). There is also some degree of dementia; many illnesses are said not to affect the mind, but over the years, SOMETHING seems to affect their minds -- if not the illnesses themselves. And then there are complications and conditions -- emotional and psychological -- stemming from the illnesses, and also from the confining and sedentary nature of their everyday lives. (There has been some recent research to the effect that not walking around can affect certain areas of the brain. Obviously not ALL areas -- as amply demonstrated by Steve Hawking, and by my physicist husband; instead the areas affected -- from the experience of well spouses and health care workers whom I know -- seem to involve personality and judgment.

What does that mean for visitors, especially visitors who visit on a regular basis? It means, briefly, dealing with people who, while in some respects are the way they were or would be without their illnesses, are in other respects difficult. This takes various forms. Roberta, whose father has MANY chronic illnesses, herself had a breast cancer scare. When she phoned her father to tell him that she wouldn't be visiting that week because she was having a biopsy, his one question was: "When will you be better enough to come see me?" And I recall one visiting day several years ago, when I babbled over with news of my New York vacation, describing the stores and restaurants I had visited, and the luxurious (if budget) hotel room I'd stayed in, my husband's sole interruption was "How much did it cost?" One-track minds, and often not the correct track. No fun for visitors.

Another difficult question: What to talk about? Especially if the visiting is every day? When people interact in regular day-to-day life, outside of a hospital or nursing home, they interact by DOING things -- working, playing, or just passing by. When you're confined to a bed or a room or a building, what do you do, and say?

Sometimes you can take the person on a trip. Many well spouses would raise their eyebrows at this idea, or even burst out laughing. The logistics involved are often ridiculous. Getting wheelchairs in and out of cars and the wheelchair user in and out of back or front seats is often next-to-impossible. (It was the one thing I could never, as an at-home caregiver, do.)

The sidewalk from Inglis House to the nearest mall slopes upward one way and, of course, downward the way back. Both present big problems for wheelchair-pushing; the wheelchair always exhibits a counter-force, towards or away from you.

Taking a nursing-home resident out is definitely an added difficulty, but if we

don't go out, we have to do something else. Sometimes Jeff and I, with or without our youngest son Devin, would go to the garden out in back. This garden is beautiful, expansive, and, best of all, often contains other people to talk to. On the other hand, it also contains other residents who, having various degrees of cognitive loss, have no qualms about coming up and interrupting your conversation, sometimes asking for your help in, say, lighting a cigarette or getting something out of their purses. Some visitors don't mind this, but others do. (And not minding this is not a solution...)

There are often other constraints, originating from the illness itself. Jeff couldn't be in the sun too long (M.S. is affected by heat.) At one point he also couldn't be out of bed too long (bedsore). As he was being put to bed, some aides didn't mind if I stayed in the room, others asked me nicely to please go wait in the lounge. That took away from visiting time and Jeff, the physicist part of his brain working just fine, could count the minutes, then say, "We only had two hours of actual visiting." The relating-to-people part of his brain NOT working, he didn't seem to realize that it had gotten late and cold, that I had a child home waiting for supper, and that it took time to wait for the bus.

I might also mention walking alongside a wheelchair. When there's limited hand and arms movement -- or if the electric wheelchair has been set on a slow setting to avoid bumping into things and people -- then wheelchairs have to move far slower than walking. And walking with someone who goes slower than you is in many ways more difficult than walking with someone who goes faster. It's frustrating, and sometimes you can trip. And emotionally, you realize that your paces are no longer the same, that you're becoming "separate species", as I once said in a poem and in a title chapter of "Dirty Details" -- and the spirituality of that can run thin.

2) Not only visiting, but care giving while visiting. This can include feeding, suctioning, itch-scratching, pillow and equipment adjusting, and range-of-motion (There was never, at least not for Jeff, enough P.T.) These caregiving duties are nowhere near as untenable as at-home care giving can be -- certainly no "nights, lifting, and toilet" (although I had to be assertive about refusing to deal with catheters that fall off, or that he THOUGHT MIGHT have fallen off). And it's very nice to know that you can call for help, that help is right out in the hall (even if not as close time-wise as space-wise).

Still, visiting does mean care giving. And for some, this "residual" care-giving is too reminiscent of the at-home care giving experiences we've just been through, and we can feel a little vulnerable and uptight about it. Even without the caregiving, "visiting a sick person is hard," says Roberta, with the emphasis on that last word. "It's like a day at work -- and unpaid."

Sometimes the most difficult part of the “visiting job” is leaving -- that is, ending the visit. The person being visited doesn't want you to leave. He often feels panicky, and shows it by making last-minute request upon last-minute-request, to keep you there just a little longer. “Couldja just put the blow tube a little more towards my chin -- No, down more -- No, more to the left -- No, MY left -- Oops, my leg just spasmed. Couldja just...?” Sudden coughing, gagging, the need to suction. The visitor feels the hopelessness of it all, even if she doesn't have issues of guilt -- guilt, that is, for not staying longer, for not staying forever, for not being sick herself, for not being able to cure her sick spouse, for not being God. She feels the hopelessness and sometimes can't bring herself to leave.

Jeff liked to keep the door closed when I was there. I complied, at least at first, but it made me feel a little uncomfortable. I didn't really want to be left alone with him; it felt too much like when he lived at home and the home health aide wasn't around. Something Kafkaesque also would occur to me: Suppose something happens and he dies right then and they accuse me of killing him, of pulling the plug (even though there was no plug to pull). When you're a well spouse, the world feels more Kafkaesque, more capricious, than when you're not a well spouse.

Visiting is certainly a responsibility, and it can feel like a burden. I think of the head nurse in Jeff's unit: “Gee, Marion,” she once told me, “I can't imagine what taking care of Jeff would be like if it weren't for your weekly visits...” So I guess I was an important part of what they call “the caregiving team” (even though I wasn't paid).

3) Visiting means visiting the ENTIRE nursing home, not only “your” resident. I've already mentioned life out in the garden, how if you're the only able-bodied person around, it can feel a little scary. The first half-year Jeff lived at Inglis House, a guy used to ask me, and sometimes my daughter, to please help him light his cigarette. Finally another resident called out to us, “he can do it himself. He just likes it when women help him...” This to me was for too reminiscent of a waking dream described in “Dirty Details,” about being the sole care giver for a roomful of disabled men, some of them demanding that I help them jerk off. It felt, in other words, a bit like rape, certainly harassment.

Visiting a nursing home resident means walking the hallways. It means seeing what you see and hearing what you hear. It can mean feeling grateful for your own life and health But it also sometimes means policing wheelchairs. Even with wide hallways, how many wheelchairs can pass a given spot at a given time? Especially if one (or two) of the electric ones stall? Or the non-electric ones get caught on each other, or on a Hoyer lift or some other piece of equipment temporarily standing in the hallway? Years of that can grate on you

and, at least for me, it smacked of being “before my time”.

When Jeff first entered Inglis House, I formed friendships with several of the residents. Bob used to give then-eight-year-old Devin food and candy; Tanya used to show me her long manicured nails, while I’d just as proudly show her my “short, cute, liberated” nails; Mary and I were agnostics together and sometimes we’d laugh about it. But soon Tanya and Mary became more demented, Mary’s speech hard and harder to understand. Both looked pretty much completely disheartened. And Bob died. In general, relationships with residents are quite temporary. And I got more and more tired of it all.

In other words, it was enlightening for awhile. And it was a learning experience for awhile (although not exactly the kind of learning experience one would need upon “graduation” from the all-too-similar learning experience of at-home caregiving). After a decade things take their toll. “Been there, done that.”

4) Being a family member means being on call when NOT visiting. Sometimes this can amount to caregiving. Around 11:30 P.M. one evening shortly after Jeff began to live at Inglis House, my phone rang. First there was silence, which led me to correctly guess who it was. Then I heard Jeff’s one sudden, weak, desperate (and typical) word: “Mar?” Then an aide got on; “Hello, Mrs. Cohen? I’m very sorry to disturb you. We’ve changed the respirator settings because it was indicated, and Jeff’s worried that he can’t breathe.” In the background I heard the continual “Mar? Mar?” “He’s panicking,” the aide summed it up. “Oh,” I said, and summoned my calm reassuring voice, which I knew would reach Jeff through the speaker phone. “Jeff, it’ll be all right. They’ve got it right. Just tell them calmly what’s bothering you and they’ll take care of it. It’ll be okay.” I heard Jeff calm down, and the aide told me, “Thank you very much -- and good night.” I knew that by “good night”, she truly meant “HAVE a good night.” And I thought that was great of her.

Being a family member also means getting phone messages. “We thought you should know: Bob was rushed to the hospital this morning.” Norma counted 45 times that the message also included, “We suggest you get here as soon as you can. This could be it.” Norma soon took this in her stride. Her secret, she confided to me, giggling, was to pretend she wasn’t home, pretend she never got the message.

At Inglis House they were usually very considerate and wise. They would end their message with things like “it’s not serious; you don’t have to come in. We’re just letting you know” or even “You don’t need to call us back.” I appreciated their consideration and wisdom. But, it did get repetitious.

5) There are even further responsibilities. For example, legal responsibility

-- powers of attorney, wills, advance directives. And financial responsibility, and worries. How to afford everything. Filling out Medicaid forms, doctor's forms, disability benefits applications. And what if they change the Medicaid laws?

And there is responsibility for managing other, NON-principal family members and friends. Answering questions -- simple ones with complicated answers such as "how is he?" uninformed ones with simple answers, such as "When is he coming home?", questions nobody knows the answer to, such as "What causes M.S., anyway?" and "how much longer is he gonna live?", slightly critical, incriminating ones like "Shouldn't he be having homemade blended food in the feeding tube?" or "Didn't you ask the doctor?" or "Have you investigated alternative forms of medicine?" or "Have you read the latest medical research?" It can get more subtle, depending on family and friend dynamics.

From "Rough Crossings", page 8: "...Very few caregivers felt that their friends and family members acknowledged their stress and frustrations. In fact, one man said he thought that, as a care giver, he was 'invisible' to everybody else. No one asked how he was. He said friends called at night after he had been at work all day and then at the hospital until late in the evening. He said they just asked about his wife and they only wanted to hear good news. He began resenting the calls. One woman, who has several close friends, was so worn out answering her mother's questions and dealing with doctors and therapists that by the end of the day, she said, 'I literally couldn't speak [to those who called] because I had no saliva left in my mouth.'"

And there is responsibility for keeping troublesome "friends" at bay. Renee's ill husband selected a completely wacko psychologist; any sane objective person would agree. Somehow her own personal needs and agenda, which she did not recognize or understand, seemed to involve manipulation of other people, and being in some kind of competition with her clients' families. In Renee's family's case, she convinced Renee's M.S. husband that, in lieu of going to live in a nursing home, he was a sure-fire candidate for independent living. All other friends and professionals strongly disagreed, but Tim was (dementedly) motivated by nursing home fears, and by her manipulations. At his and his family's expense, he was set up in an apartment with attendants coming in and out. Two weeks later he was home, tail between his legs; the attendants and other people involved had been mostly druggies, and definitely incompetent and untrustworthy.

My own husband, back when he was not yet living in a nursing home but was (I believe dementedly) motivated by nursing home fears, became prey to a couple of needy "friends", friends whose "need" was to feel "needed". The three of them somehow denied that most insurance policies don't pay for 'round the

clock at-home custodial care, and spent hours and weeks on the phone trying to arrange this non-existent service, not taking “no” for an answer and trying to involve me in the deal. Like Renee, I finally had to put my foot down.

Once he did live in the nursing home, there was a period of over a year when one of these same “friends” tried to improve Jeff’s feeding-tube diet. The situation escalated. He convinced Jeff of things which seriously impaired his health; in particular a very large bedsore resulted. I finally called an Inglis House meeting -- all Jeff’s caregivers on his wing, the director, me -- everyone except Jeff and this friend. We all devised legal and other ways to put our feet down, and this included barring the friend from visiting for awhile. Sanity, wisdom, and professionalism usually do prevail, but only with time, and at the initiation of the principal family member.

The last, but far from least, perhaps greatest, responsibility of a family member is the responsibility -- sometimes real, sometimes perceived -- of seeing that the nursing home staff is doing a reasonable or adequate job of caring for the resident. To various degrees, and to various degrees of warranted-ness, family members have been dissatisfied with the kinds of care being given -- either a particular incident or in general -- and have brought complaints -- sometimes strategically, sometimes not -- to the aides, nurses, head nurses, directors, and so on. Again, sometimes the complaints are warranted, and sometimes they come out of the complainers’ frustrations and agendas, sometimes a little of both, and sometimes the PATIENTS, in “tattling” on the aides, are (dementedly) exaggerating or even lying. It’s on the family member to sort it all out and to act accordingly. This is a big topic. I’ll return to it in the chapter on Suggestions for Those in Charge), but it certainly needs to be listed here as a family member responsibility, and it also needs to be mentioned that many family members would rather not have that responsibility. They would like to be able to feel confident and to count on the facility to do its job.

Fear has a lot to do with it. “Many care givers fear that their loved ones will be neglected in hospitals and nursing home.” (ROUGH CROSSINGS; Family Caregivers Odessey’s through the Health Care System). “A transition to an institution means extra vigilance for the caregiver.” Caregivers even fear that “the patient might actually be harmed.” ROUGH CROSSINGS also gives examples of family members who paid nursing home aides for “extra” care.

“Advocacy”, as it’s often called, is indeed a form of care giving. Many family members I have known say that, because of the necessity for it, their lives are no easier now that their relative is in a nursing home. One reason might be that they feel no less powerless.

Besides physical duties, there are emotional tolls that family members pay.

And besides the more obvious emotional side-effects such as grieving, fatigue, frustration, anger, sadness, disgust, loneliness, and so on, there are less obvious repercussions, many of which have to do with family member IMAGE, both self-image and societal image. How does it feel to suffer guilt and/or reprisal for: (1) not being as sick or not suffering as much as your resident, (2) maybe not feeling as compassionate toward your resident, and the other residents, as you think you "should", (3) maybe not really wanting to visit your relative in the first place, (4) maybe not loving, or even liking, your relative, and (5) maybe even wishing your relative would die already.

And how does it feel to not be appreciated (let alone paid) for what you're doing? Or to be appreciated, but not really enough, or not for the right things. (For example, people and readers often appreciate that I cared for Jeff so long at home, whereas what I'm really proud of is that I chose to STOP, and to write about it.)

How does it feel to be placed, at best, second? Right or wrong, I used to get annoyed about the matter of the cookies that "the kitchen" at Inglis House would send to the various floors and units. "They're for the people visiting," one of Jeff's aides had kindly -- and wishfully, it turned out -- told me. "How nice," I'd commented -- naively, it turned out. For other aides later told me that the cookies were "really" for the residents. I couldn't understand HOW that could be, since they were kept on the top of the fridge, definitely not wheelchair accessible. Mixed messages, at the very least, and rather illogical. At any rate, I sometimes got annoyed when I was told that they weren't for me, or when "the kitchen" forgot to send them.

-- "No, Marion," said even Norma. "You shouldn't get upset about the cookies. You've been in this business TOO LONG! Bring your own cookies; you shouldn't expect the nursing home to take care of YOU." Indeed.

Maybe, too, I'm wrong about the Family Members Recognition Event, or anything about or for US. But I don't believe so, and neither does Dr. Brennan. "Absolutely," was her response to my assessments. "They SHOULD have cookies for the family members. It's a very small thing, to show their appreciation."

Likewise, Dr. Brennan agrees that I should indeed have felt annoyed when I first walked in and the aides would call out variations on, "Hey, Jeff, your WIFE's here." "Ooo, I know how happy you are to see your WIFE." "Just lookit the smile on his face; that's 'cause his WIFE's here." And indeed, there was a big grin on Jeff's face (maybe a slightly demented grin), and not very flattering to me).

I do think it's wonderful that the staff is so attentive, but in some situations I

can't help wondering, "attentive to WHOM?" Did anyone notice (and in fact, I had talked to some of the aides about this) that I wasn't particularly happy to be here? Did anyone ask? Could they sense that I didn't want references to anything romantic between Jeff and me, because that might cause him to act romantic and I didn't feel romantic? Had they read any of the Well Spouse literature, or even some medical literature, that tells of changing couple dynamics in the face of chronic illness?

"All that's for Jeff's benefit, not yours," offered my friend Freda, by way of explanation. Again, indeed.

How does it feel, for nothing to be for YOUR benefit? Moreover, what does it mean for our self image, when we're coupled with someone sick/demented/deficient/needy/etc? What message do we get, especially over time? My own word for the message that we get is "downtrodden". Downtrodden by association. Even after nursing home placement, we are still fighting downtrodden. As the Well Spouse foundation motto says, "When one gets sick, two need help." Or "when one gets sick, two get downtrodden."

Also, how does it feel for a family member who is herself a professional to, every time she walks through those doors, be instantly "lowered" to the rank of "client". One could say it doesn't matter. One could say everyone has to be humbled. One could go so far as to say it's good that she's forced into this humbling situation. But these all feel like non-answers. For example, is the extent to which a professional NEEDS to be humbled a function of whether or not she's a family member of someone in a nursing home? (Especially since she has ALREADY had her share of being humbled) And aren't there OTHER, non-family-member situations in which she's humbled? And yes, it often DOES matter. If it matters to the person, it matters.

Almost all of the staff at Inglis House realizes this. For example, they almost always addressed both Jeff and me as Dr. Cohen. But it was annoying to me when one doctor absolutely refused to! The first time that I corrected him, he answered, "Well you're ALSO MRS. Cohen." "And YOU'RE also MR. Rosen!" I answered, but the confrontations were repeated. I don't know why it was so important to him that I be Mrs. Cohen. I was advised to report him, but didn't. He was a good doctor and Jeff needed a good doctor.

Here's another example of how low on the totem pole family members can get: Forget cookies! Think about free meals! "Providing family members with meals seems a very basic thing," says Dr. Brennan. Yet it's often the official policy that volunteers get free meals but family members don't. What message does that give the family members, who often do and have done at least as much as volunteers, and over a longer time period? Moreover, like volunteers, family members don't get paid. Why aren't we also given free meals -- and recognition

events?

Okay, I have at times thought bitterly: There IS a difference. Volunteers have a choice. Family members don't. (Or they think they don't. Or society wants them to think they don't.) So for that reason it is impossible for family members to be volunteers.

What would happen if a family member applied to be a volunteer?! That is, if she volunteered to spend time with her relative, and not, specifically, with any other resident? Would she be laughed at? "What?! You can't VOLUNTEER to visit your husband. You HAVE to visit your husband." Indeed. Would her application have a prayer of a chance of being accepted?

"We don't have the funds to feed the visitors," I've been told. But are there more visitors than volunteers? (In Inglis House there probably weren't. Most residents were visited very often.) And why do HOSPITALS often give visitors meals, if asked? And mainly, why DON'T the nursing homes have the funds to feed visitors? Is it a matter of priorities? Then why, again, are visitors low-priority? And why doesn't it seem to matter, that that's the message we're getting?

Perhaps the sad answer is that free meals are perceived to be an incentive to be a volunteer, whereas "they" don't need to offer incentives to be a family member; reality, or society, has already done that -- meaning that, again, family members have no choice.

Concerning the idea of a Family Member Recognition Day, some family members have countered, "I don't NEED recognition." But it's not only an individual matter; it's a universal and political matter. And I have to admit that, while I also didn't NEED recognition, I WANTED recognition. Moreover, do VOLUNTEERS need or want recognition?

After I did that big poetry reading in their main hall, it got back to me that one of the administrators at Inglis House felt that I should not have asked to be paid for that reading. I'd previously, BEFORE Jeff was a resident, been paid to read at Inglis House but now, "after all Inglis House has done for Jeff" is what got back to me.

"What?! You're separate from Jeff," is how another well spouse reacted, when I told her. And was that administrator saying, "She should be grateful" or even "she should know her place." Does this smack of Dickens; "please, sir, may I have some more?"

Did I owe Jeff's debts? (assuming Jeff had debts). Could I be put in debtor's

prison? But I thought that was no longer the law.

I certainly HOPED I didn't owe debts, because if I did they were far too vast to ever pay off. I could never ever for the rest of my life charge for readings or for copies of my books or for anything at all, ever. I could never ever be paid for any work I did. I would "owe my soul to the company's store." And I would feel enraged and hurt.

That administrator was wrong. In fact, Inglis House was paid for "all it's done for Jeff." And I have never been paid for all I'VE done for Jeff. Never.

CARE GIVING AS A WOMEN'S ISSUE

Is care giving a women's issue? Many of the members of the Well Spouse Association seem to believe so, and I do too. That their majority is female, and that the Foundation has noticed this, certainly says something. Likewise the fact that, at its Annual Convention in October, there are often separate workshops for men and women.

After the '98 "For Women Only" workshop, facilitator Lilly Cohen made up a Summary of Discussion' and soon mailed it out to the participants. "Our mandate was to discuss the unique problems of female well spouses," she explained, and went on to list some of them: "Hard to ask anyone for help," "dependent on adult children," "role reversal," "cannot keep promises to young children," "strong is lonely" (as, very possibly, men could attest to), "I am Amazon, I am invincible, I am tired.", culminating in "women are programmed to be caregivers." Indeed, the many "simultaneous demands" on women correspond to their many conflicting roles, whether or not they're well spouses.

I was at that workshop and in my notes appears a much-quoted quote: "When chronic illness strikes [in a marriage], the women's mindset is [encouraged to be]: I'll stay home and take care of him. The man's mindset is [again, encouraged by society]: I'll keep working and hire someone to take care of her" [or have her live in a nursing home]. (There are exceptions, as evidenced by the male Well Spouse Association members, and no doubt expressed in the "For Men Only" workshop). Moreover, women are often expected to be caregivers to their husband's ailing PARENTS, while the latter "remained largely uninvolved themselves". (ROUGH CROSSINGS, p. 7)

"The majority of caregivers are women," says psychologist Linda Welsh, in "Chronic Illness and the Family", "not only because they live longer than men, but women tend to stick out the relationship longer when the going gets tough."

HOW are women "programmed to be care givers?" In this society, women in general are viewed as caregivers in so many subtle ways -- mothers, nurses, kindergarten teachers, volunteers of various kinds, and so on (not to mention the psychological caregiving that more women than men seem to provide, often to spouses, ill or well), so if a woman's spouse becomes physically chronically ill or disabled, she is expected to become an ACTUAL caregiver. It's just assumed. All of a sudden women are NOT frail or weak; all of a sudden they can lift upwards of a hundred pounds. All of a sudden no one asks questions about this female weight-lifting; all of a sudden there's that conspiracy of silence concerning it, and concerning most of the other "dirty details" of caregiving. That, indeed, is probably a good chunk of reason why chronically ill and disabled men, including

Christopher Reeve, are told, by agencies and insurance companies, "Your wife can do it." And then, if and when she does, it's just taken for granted; she's not truly revered or respected; she's only doing her job (whereas when a man does it, so well spouses have reported, people drool, "Oh, isn't it wonderful? He's staying home and taking care of his wife.")

One might go so far as to say: All women are in danger of becoming care givers. All men are, too, but not to the same extent. For example, at the '98 "For Women Only" workshop, Patricia described "the parallel toilet syndrome." "I put him on and I sit on the other. I hear him flush and I think, 'Well, I'm done!'" I recall the familiar laughter of everyone present, indicating how we all understand that even our private moments are not quite our own. Could a male well spouse have said the same thing? Of course. But again, the statistics are in; more at-home caregivers are women.

Anita Gonzales also made us laugh -- the too-familiar well spouse laugh -- as she described her own life. "I feel like Superman. Out in public I'm Clark Kent - - smiling when people say "he looks really good" -- but I'M the one who [behind the scenes] GETS him looking this good."

Along these lines, Maggie Strong, author of "Mainstay: For the Well Spouse of the Chronically Ill" and founder of the Well Spouse Foundation, often talks about "well spouse invisibility." (The most familiar example cited is "no one noticing the person pushing the wheelchair.") Well spouse invisibility is but one example of the (relative) invisibility of women in general. Thus, invisibility hurts us all the more because of our invisibility HISTORY; we're WORN DOWN with invisibility.

During the seven-year period of my own at-home caregiving "dire straits," many of our friends, and even my own friends, used to say "He CAN'T go into a nursing home; how would he do his physics?" and not "He HAS to go into a nursing home; otherwise how will Marion do her writing?" Somehow "writer" doesn't carry as much clout as "physicist." Or perhaps "woman" doesn't carry as much clout as "man".

Sophie, a promising and avid sculptor, was a well spouse for thirty years, long before the term "well spouse" existed. Now that her husband has been dead for over a decade she talks about how "horribly guilty" she feels. "I was a mean caregiver," she says. "I did everything but I didn't do it lovingly." Intellectually, her positive self-image and feminist consciousness tells her that she is not guilty. But it's hard for her to drown out the voices of her son and daughter, other relatives, and "friends" who had expected her to do it, all of it, without help, appreciation, acknowledgment, and without complaint or questioning. She goes on to manifest more of her torment. "You know, you never remember how

hard it was; you don't remember the bad things. What you remember is how bitchy you were, and you wonder, 'Now, what was I so bitchy about?'

Is it the human condition, or society, that's sending my friend on this guilt trip? What is the proportion of each in this scenario? Is it an accident, that this friend is a woman?

Unlike my friend, I had support from family and friends. Although this support didn't usually take the form of physical help, they didn't expect me to do the caregiving as a matter of course. However, society as a whole seemed to, and this was a source of much anger, and much "bitchiness" on my part. One morning in 1992 I was in the midst of making breakfast with the kids when our home health aide came halfway down the stairs to announce that the visiting physical therapist (covered, at least for the time being, by our insurance) wanted me to "come up for a minute to learn some techniques."

I was furious. The way I looked at it, the more they KNEW I could do, the more they'd expect me to do, and I resisted this role all the way. "I don't have TIME to learn techniques," I grumbled. "I have a Ph.D. I've done enough learning. Besides, I'm the one who's been doing it all for five years. How about I teach HER? And how about, while we're at it, I get paid for teaching her?"

Why was I so angry? Why, indeed, are women always so angry? Upstairs, after breakfast, I calmly told the physical therapist in so many words that indeed I had been doing for years what she was about to show me, and then some. She nodded. "And I guess," I added, "the reason you wanted me to come up is that this is your last visit and you want to make sure I know how..."

She nodded again. "Once a month," she answered. "I'll be back once a month just to check that..."

"-- that I'm doing it correctly ?" I interrupted furiously and bitterly. Just to check up on me. To test me..."

"Oh, no," she tried to assure me, not quite getting the point, not at all catching my tone of voice, and completely ignoring my anger. "Not to test you. Only to see..."

"--that I'm doing it right?" I interrupted again. "Look, if they're so afraid I won't do it right, then why do they let me do it in the first place? Why, in fact, do they MAKE me do it? Because, actually, if truth be told, I don't WANT to take the responsibility." (Indeed, do caregivers have the privilege, as citizens often seem to, to declare, "I'd rather not take on the responsibility.")

The physical therapist shrugged. "In fact," I continued, "if I DO do it wrong

and something bad happens, I hope I don't get prosecuted..."

We both shrugged again. It felt to me, as it often felt to me in those days, as though the system makes us do what we do without giving us the credit, or the acknowledgement, or enough help for doing it. A phrase about motherhood comes to mind, from Adrienne Rich's book, "Of Woman Born." That phrase is "responsibility without power." Without power, specifically, in the form of acknowledgment, prestige, and help, or pay.

In fact, caregivers are often **BLAMED**, and women well spouses more than men well spouses. "You're not responsible for the **RESULTS** of your care giving," said minister, writer, and well spouse Harry Cole, but it seems we are often held responsible for our **FEELINGS** about it. At a well spouse support group meeting it was a male well spouse who, in the midst of what he possibly thought of as "complaining," began, "have you tried this? Did you ever try that?" As though our problem was stress rather than dire straits. "You know," he continued, "all this is really our fault, all of us. We could be helping each other."

And was it an accident that it was the **WOMEN** well spouses who became instantly livid? "Are you kidding?" Debbie gasped. "You mean I have to baby-duty **HER** husband, too. No thanks!" "I have enough on my hands with Harry," laughed Flora. "I don't need **JEFF**, too."

At one point someone told the guy who had unintentionally begun this rumpus, "You're blaming the victim." Indeed, "blaming the victim" is something that seems to be done to women more than to men. In general, guilt trips seem to be laid on women more than on men.

Another way in which being a caregiver seems to connect with being a woman is in the issue of abuse. Is being told, expected, or forced to be a caregiver a form of abuse? If so, abuse from whom? Who is the abuser? In "Dirty Details" I relate how, one day, after a particularly grueling day toileting, lifting, company for dinner, plus broken VCR, I had a temper tantrum to end all temper tantrums. I was so upset and angry that I specifically **TRIED** to make this tantrum top all others; I just had to express that this was the worse yet. And I succeeded. The cops came to the door. "Someone heard a woman screaming," they said.

"A woman **WAS** screaming," I told them, shrugging.

"Were... were you screaming?" they pressed.

I shrugged again. "If you lived this life, with a husband sick like this for so long, you'd scream, too."

"Are you all right?" one of them asked.

And I couldn't bring myself to say yes. I was not all right. I felt abused. Beaten. I needed to be rescued. I could only keep shrugging until they left.

I understand now who the abuser is, and still is, for so many caregivers, women and men. The abuser is society. In particular, the abuser is a health care system who allows caregiver after caregiver to go through these "dire straits," which shows up once a month only to check that the care receiver is getting the correct physical therapy from the caregiver, and who never comes to check that the caregiver is getting enough sleep. A system whose cops cannot rescue the caregiver. A system where 911 makes an incorrect decision to send the care receiver to the hospital and then the hospital blames the mistake on the caregiver.

This type of abuse" can feel a lot like rape. Toilet in particular can feel like rape; after all, this is physical contact which a couple does not choose, which it is forced to submit to in order for the ill person to live at home, and even after the point is reached where the caregiver no longer *wants* the ill person to live at home.

In fact, as is usually the case in situations like this, there was a period when Jeff did not agree with that "nursing home decision" and so I felt raped by him, too, not only by the system. One evening, after some lengthy and ugly outbursts on his part, I felt horrified and afraid, extremely conscious of his power to continue, as I thought then, to hurt us (meaning the kids and me). "Oh my God," I thought. "He can hurt us, he MAY hurt us, he's ALLOWED to hurt us."

Society would LET him hurt us, would not even begin to protect us. I remember fantasizing and plotting an escape. Indeed, a care receiver seems to possess a certain kind of power. The power, for example, to call the caregiver at any given moment, wherever in the house the caregiver is (and she usually feels that she has to answer asap because there was no way to know, not. All I heard was "Mar", no specifics.). The power to control when a family can go out in the morning or to sleep at night, and whether, during the day, it can have an uninterrupted game of Scrabble. As with a baby, but without the cuteness of a baby, and without having made the decision to have the baby, the entire household revolves around the ill person.

"Mar," I'd hear. "I think I need to sit on the toilet." (And of course "think" rather than "know" was enough to get me racing.) I'd put him on, he wouldn't need to go, I'd take him off, fifteen minutes later he'd call "Mar" again (Another "think," rather than "know."), again he wouldn't really need to go, and when, the third time I was literally crying from fatigue and frustration, he'd tell me, "If you get me all upset I won't be able to go." "Controlling" is the word. The Bible says, "the meek shall inherit the earth," but that doesn't make it right!

Sometimes abuse takes the form of flattery (and the abuser gets upset if we're not flattered). "No one can cook quite like you." "A child needs its mother." "Negroes' skin can take the hot sun." And when you're a well spouse, you're a "strong woman." Yes, because of what we've been through, and probably because we do lifting, society calls us strong. Most well spouses whom I know don't *want* to be strong. We want, like most human beings, to have moments or hours or perhaps longer periods of being weak, or being *permitted* to be weak. For one thing, although strong is not the opposite of tender, much of society perceives it as such; do women well spouses feel the need to go overboard and try to appear tender or feminine?

Back to abuse, and also forwarding a bit to the "nursing home decision chapter", especially the question, "Why did you stay so long?" that question has a feminist answer and takes the form of another question: why does *any* abused person stay so long?"

She stays because getting out of it seems or is hopelessly impossible, because she's tired, and/or because she's worried about future guilt feelings, and about regret. Sometimes she stays because she's in love, or thinks she's in love, or wants people or society to think she's in love. And mostly, she stays because she isn't SURE she's abused; she doesn't know 'where she stands. She stays until she does know and then she stops staying.

Sometimes it seems as though the treatment of and attitudes toward caregivers is the very epitome of woman's oppression. Or maybe it's only a microcosm of, or metaphor for, woman's oppression. The parallels are manifold: Caregivers are put on a pedestal, while at the same time degraded. Caregivers are criticized for complaining or for being angry. Caregivers are held responsible but powerless. Guilt trips are laid. Victims are blamed.

Perhaps, even, caregivers' oppression is one of the more obvious forms of women's oppression. Perhaps it even PROVES the fact of women's oppression. A recent review (otherwise favorable) of "Dirty Details" refers to the reader's possible "annoyance at her overbearing manner." This seems telltale. Especially considering that, on the same page of that publication, appeared another review of a trial account titled "Principal Suspect." "Riveting," they call it - meaning FAVORABLY riveting.

Hm. When it's a trial, or a murder, or a war, it's "riveting." But when the "dirty details" are domestic (and about a woman) it's "overbearing," perhaps annoying. Double-hm.

Does making your point mean being "overbearing?" (Just as describing something well and convincingly seems to mean "complaining") In order to not be

angry, complaining, or overbearing, must we fail to make our point?

How much of a feminist issue is all that? Well, criticism of women who are “overbearing” in OTHER ways -- too fat, too loud, too smart, too sexual, too sad, too happy -- is nothing new. And, again, what do reviews say about MEN who are “overbearing?” DO they say men are “overbearing?”

Another telltale excerpt from a “Dirty Details” review: “What might have given the book more pathos is a chapter from Jeff.” In fact, my editor and I had taken great pains to include some of Jeff’s story; that was hardly avoidable, anyway, since the book was an account of our entire family’s experience. Indeed, the subject of the Introduction and first chapter was how Jeff and I met, and what our life was like before he got M.S.; also, the book includes a 17-page gallery of family photos, and Jeff, along with me, is on the cover. So yes, there was a lot in the book about Jeff, but the book as a whole is not ABOUT Jeff. But perhaps the reviewer wanted it to be. At any rate, how MUCH of Jeff did she want? Would ANY amount have been enough? Would a book by, say, a molested child, be criticized because it didn’t give enough “voice and personality” to the molester?

Perhaps this society, including the women’s, feminist, and humanist movements, is still in the era when trying to liberate oneself from an abusive relationship or an oppressive society is USUALLY more than okay, but the special case of trying to liberate oneself from CAREGIVING is a bit too much. It seems that the newer and less popular the struggle, the more the strugglers get criticized.

Women are often put in the position of being the bearers of bad news. As mothers and teachers, we have to inform young children that certain delights are dangerous or unhealthy and therefore no-no’s. As receptionists, we have to act as go-betweens, sometimes explaining, “it’s not a policy I agree with, but I have to enforce it.” As hostesses, we have to apologize for burnt casseroles or underdone turkeys.

In certain past societies the bearers of bad news were punished, sometimes killed. In general, human beings often can’t help but feel angry at the bearers of bad news, even writers and activists who are doing society a service by sounding the wake-up calls (being whistle-blowers). “Brace yourself,” says another review of “Dirty Details.” “Marion Deutsche Cohen’s blunt and wrenching memoir ... is not for the squeamish.” This appeared alongside and opposite reviews of books about poverty, war, torture.

Why, suddenly, is everyone so “squeamish”? Why, suddenly, is the author “overbearing” or “hard and edgy?” Why all the resistance? Why is yet another

horror so hard to take? Especially a horror which so many people experience, if not first then second-hand? Or perhaps that's precisely the reason, because it's something which so many people actually experience, and people would rather not KNOW that it's a horror. (Who needs to learn about yet another horror?)

How resistant, still, this society is to self-advocacy! Indeed, self-PROTECTION! How resistant, even to selves (in the plural)-advocacy – even if, in advocating for one's own self, one is advocating for the selves of ALL selves (all well spouses, all women, all blacks, etc.). And even though (or, again, perhaps BECAUSE) “the personal is political”, conservative and radicals alike seem to avoid, even fear, the personal.

Self-advocacy is important for the same reasons that complaining is important. RevoLAtion / revoLUtion -- is that play on words an accident? It simply takes a shorter time for an individual to notice her/his own oppression than another's -- for sheer physical reasons as well as emotional and psychological ones. Self-advocacy gives a boost to the propagation of the message, and the flip-side of this is that for society to discourage self-advocacy is to impede social progress.

Perhaps it is this resistance to self-advocacy that has made caregiving (in all its forms, not only to chronically ill people) a women's issue, one of the most difficult the women's movement has had to take on.

IS IT NURSING HOME TIME YET?

At a Well Spouse support group meeting several years ago, Emma (not her real name) was telling us her troubles. "He's so grumpy all the time." "I NEVER enjoy being with him." "Tell me: How do you put a catheter on an 85-year-old man?!"

Many of the well spouses present gave each other knowing looks; a few then turned to Emma and gently asked, "Is it nursing home time?"

Instantly Emma calmed down and made an about-face, as though suddenly getting cold feet. "Oh, he's not ready for a nursing home yet."

At this expected and normal response Norma, one of the more seasoned well spouses, quipped, with typical Jewish gestures and inflection, "Oi, they should have a special nursing home for people who aren't ready for nursing homes yet!"

Laughter rippled around the circle, followed by smirks and shrugs, especially on Emma's part. What was the joke? And what was the serious meaning behind the joke?

Freud said that most dreams have more than one meaning, and he probably said the same thing about jokes. Here are some meanings behind Norma's rather telling joke:

1) "They should have" means "Emma needs" or "well spouses need" or "well spouses wish they would have" -- all independent of whether or not EMMA'S HUSBAND is "ready for a nursing home." "It is often the case," says Dr. Brennan, "that the ill person is unable to perceive and acknowledge the consequences, to the caregiver, of at-home caregiving." Thus, if a caregiver holds her breath waiting for her care receiver to announce that he's "ready for a nursing home", she probably won't survive the breath-holding!

2) Whether or not it's "nursing home time" is a different question from whether or not the ill person is "ready for a nursing home." This is true whether "ready" means "physically ready" or "emotionally ready." "Nursing home time" is signaled, not only by the patient's needs, but also by the family's and caregivers' needs, and abilities.

3) Along these same lines, custodial care counts, too. That is, "ready for a nursing home" means, not only that the patient's MEDICAL needs can no longer be satisfied outside of a skilled care facility, but also that his CUSTODIAL needs

can no longer be satisfied outside of a skilled care facility.

“Your wife can do it” (as Christopher Reeve was told by insurance companies, when asked if they covered his care) is different from “your wife can SAFELY do it,” “HEALTHILY do it,” WILLINGLY do it,” HAPPILY do it,” -- and, ultimately, from “your wife CHOOSES to do it.”

4) So in Norma’s joke, the phrase “not ready for a nursing home” could be taken as having at least two meanings:

- a) Literally -- that is, medically, physically. In this case, the joke is actually making the suggestion that there be a kind of “halfway house” -- something that, while not providing any unnecessary (and costly) medical services, does provide custodial services, and therefore relief to the at-home care giver. In fact, the system does sometimes provide this in the forms of day care or various types of independent living. Both of these, however, are often not sufficient for the well spouse caregiver -- and both involve making decisions and implementations almost as difficult as “the nursing home decision.”
- b) Emotionally not ready for a nursing home, and therefore not admitting that he’s physically ready. Sometimes, also, it’s the family members and/or care givers who, for various reasons to be elaborated on soon, deny when it’s physic-ally “nursing home time.” (As though, for example, not being in a nursing home implies not being “nursing home material” -- that is, not really being “that sick”)

In general, the lesson of Norma’s joke is to delve a little more deeply as to whether or not it’s nursing home time. And however interpreted, the joke, in the face of chronic illness, is funny-familiar. Many well spouses and caregivers say “s/he’s not ready for a nursing home yet” or “No, it’s not nursing home time yet,” when in fact he is, and it is. The remainder of this chapter is devoted to exploring that phenomenon. Why the hesitancy? Why the denial? What are the fears? What is the politics? Why is it so hard to let go?

Nancy Wallace, author of CHILD’S WORK and BETTER THAN SCHOOL (books about home-schooling, childhood, and parenthood) and, more importantly for our purposes, someone who has had experience with various life situations, once said, “There’s always all this fuss about whether or not So-and-So should go into a nursing home but then, once he does, everything’s perfectly all right.” Here are some of the obstacles (real and imagined) that prevent people from reaching that desirable state. (In the final chapter, “Suggestions for Those in Charge”, I talk more about what to DO about these obstacles.):

l) Mis-information about financial matters: Probably the most cited obstacle to nursing-home placement is money, or lack of. Indeed, nursing homes charge anywhere from \$3,000 to \$11,000 or more per month. Many at-home caregivers have read or heard this, and if not they can pretty easily envision, from their own care giving experience, the phenomenal costs of the physical care of an individual who, for the most part, cannot take physical care of himself.

But what many at-home caregivers do not seem to know -- or at any rate, do not seem to keep as a mindset -- is that this charge is almost never born by the family of the resident. ("Private pay," as the term goes, is quite rare. Ask any director of or worker in pretty much any nursing home.) It seems strange (though true) that, while Medicaid is very common knowledge appearing constantly in the media and in politics, few families seem to internalize this knowledge; "I can't afford a nursing home," many family members and caregivers repeatedly insist.

Also, once people do concede that Medicaid exists, they then proceed to persist in believe that it's out of the question. I've often heard "They take away your house, your car, all your savings." In actually, house, car, and many other items including, up to a point, savings are "protected" under the Medicaid laws. Medicaid specifically does NOT count houses and cars as "assets," to be "taken away".

It IS true that going on Medicaid can be both a nuisance (in paperwork) and a drain on larger amounts of savings. Moreover, it can be, or feel, degrading and enraging, as many aspects of your life are checked out by social workers (albeit, so I've heard more and more lately, often sensitive and supportive). It can also feel scary, especially since Medicaid is, in many families' experience, a first-time, untried, and unknown quantity. More limitations of Medicaid will be discussed in the "Suggestions" chapter, but the disadvantages, still, are often exaggerated in the minds of people who are emotionally resisting "nursing home time."

"Health care professionals," suggests Dr. Brennan, "could, in the face of chronic ever- progressive illness, support caregivers by taking the stance that it's no longer feasible that the caregiver continue to provide care because the consequences to the caregiver -- physical, emotional, social, and spiritual -- have become too great. Professionals should be sanctioned by institutions to work with caregivers at critical points; it should be part of the Visiting Nurses Association activities. And hospitals should have family therapists on their staffs."

As things are, though, the bottom line, money- and Medicaid-wise, seems to be that one of two phenomena happens:

A) The family members of a "nursing home candidate" strive to inform themselves of the particulars, and might begin to feel reassured once they have

(and talking to an elder care lawyer is an essential part of this process); they might, however, still feel some residual hesitation and fear. But eventually they inform themselves more and more, think things over, and then make “the nursing home decision.” In this case financial and other practical realities often do further DELAY “the nursing home decision” but don’t permanently prevent it.

B) “The nursing-home decision” is prevented entirely. Sometimes, in fact, financial considerations are used as an excuse, or rationalization. I’ve heard “No matter how bad it gets, she can’t go into a nursing home because we can’t afford it”; people seem to holding stubbornly to misinformation.

2) Another obstacle to making “the nursing home decision” (no matter how vital it is) is misinformation, not so much about financial matters, but about what “nursing home time” means, what the whole nursing home scenario is like. Some of the more common misconceptions here are:

A) that nursing homes are only for old people. In reality, some people who are “nursing home material” are young, even teen-agers or children. Inglis House (where my husband lived, along with hundreds of other people under 50, and some over 50) was specifically set up for “non-old” people with disabilities. Take a minute to think about it. *Of course* young people can become quadriplegic and/or brain-damaged through, for example, auto accidents. *Of course* cerebral palsy starts at birth. And the average age of onset of multiple sclerosis is mid-thirties.

In fact often, precisely *because* these chronically ill and/or disabled people are young and therefore will live a long time (often a natural life span), their spouses and families are less likely to be able or even willing to care for them for the (long) remainder of their lives. That is, for young ill and disabled people, it is, in some sense, even more important for the family to put mental and emotional energy into the nursing home idea.

B) that the purpose of nursing home is to provide medical care. Again, many chronically ill and/or disabled people require little or even no medical care. But, since they are paralyzed to various extents, they require custodial care (what I call “nights, lifting, and toilet”) which can be and usually is extremely impractical or even impossible “in a home setting.” Large expensive equipment such as Hoyer lifts, ventilators, and feeding tubes -- and space to maneuver in -- also, more than one person to, say, transfer from wheelchair to bed or clean a B. M. or a bedsore -- all these are far simpler to provide in a nursing home.

Indeed the NATURE of custodial care is grossly overlooked and underplayed in society, including health-care professionals and policy-makers

within the health-care system. “The conspiracy of silence” runs rampant, and too many families of patients requiring only or mostly custodial care are not presented with the nursing home option. Misinformation and just-plain ignorance, as to what the ultimately highly untenable alternative to nursing home is like, borders on being one of society’s greatest evils.

From page 11 of ROUGH CROSSINGS, “One daughter, whose mother [eventually] died of cancer, said she was shocked to learn that her mother would be bedridden and would need a catheter when she came home. She said, ‘I was afraid. I’m not a nurse. We weren’t trained. We didn’t even get a piece of paper about how to bathe her or anything.’”

Indeed, to provide such a “piece of paper” would be tantamount to admitting (indeed, literally “putting in writing”) the truth that perhaps the sick mother should *not* be returning home, with her daughter as care giver. Put another way, such a piece of paper could be tantamount to *requesting* that the daughter be a care-giver, and would leave open the possibility that she refuse the request. The absence of that “piece of paper” is, at best, an instance of denial on the part of the system, and is certainly an instance of “the conspiracy of silence”.

3) Misinformation about nursing homes themselves: another misconception (or in some cases partial misconception) besides those involving finances and the difference between medical and custodial care, concerns the quality of nursing homes. People often assume that nursing homes are so terrible that they would be cruel to “put” their “loved ones” into one. True, there have been “bad” nursing homes, and if you search hard enough or talk to enough people, a nursing home horror story or two is bound to crop up. So yes, there is some slight truth to this misconception (as with most misconceptions) -- namely, there are *some* bad nursing homes, and there have been bad incidents in good nursing homes. And in general, we the consumers are not always in control.

However, there are not enough bad nursing homes to justify any decision against nursing home placement. Here are some other important things to consider:

- A) There is also some truth -- these same two truths -- in the statement that the *family* is a bad environment to be sick in. That is, there have been bad families (along with “horror stories”) and there have been bad incidents in good families. In other words, a little perspective, please.
- B) The quality, or lack of, of nursing homes is often used as an excuse to further delay the nursing home decision. Again, fears and hesitations are normal and understandable, but for many families, they are so pervasive that no nursing home seems good enough for them. They are blocked on

the very idea of nursing home placement.

- C) Here's a question: IS, in actuality, "the home" and "the family" really the best place for any particular care receiver X? Is it really true that X's home environment is wonderful and full of love, or is that only an appearance that X's family wants to maintain? After all, lately especially, it has come to light that many families are dysfunctional and even abusive in ordinary situations, *without* the stresses and "dire straits" of chronic illness and care giving? Is, indeed, X's home truly a good -- or even safe -- place to be sick and die in?

4) There are also real (not only perceived) physical obstacles to making the nursing home decision, and many of them hinge on the difficulty of *implementing* that decision. Indeed, knowing that there will, or even might, be such difficulty is enough to cause already-weary caregivers to shy away from that decision. However, many of these physical obstacles are not as great as people think. In "Dirty Details" I told how I'd been under the mistaken impression that there would be a long period when I'd be filling out Medicaid forms, conferring with lawyers, contending with people who disagreed with me on the nursing home decision (such as family, health-care workers, and my ill spouse) -- all of this of a more or less unknown degree and nature -- *and occurring at the same time* that I would be doing "nights, lifting, and toilet." I hadn't realized that all "the paperwork" would (at least in my case) be done *after he was already living in the nursing home*, when I would be well rested. If I had realized this, I might have been quicker to make that nursing home decision. So fears (often unwarranted) of the difficulties of nursing home placement is a common obstacle.

Another obstacle related to implementation is not knowing how to go about initiating nursing home placement. Whom do we inform? What do we say? Since it's often the case that health-care professionals don't themselves initiate nursing home discussions, well spouses might feel hesitant or ashamed to bring it up. After all, if the professionals haven't mentioned it -- nor family, nor friends, nor even, sometimes, the well spouse's own parents -- how can it be nursing home time? (In my case, I mentioned in anyway, WHILE JEFF WAS AN IN-PATIENT IN THE HOSPITAL, and the social workers took over with the implementing. They would not have don't that if he had not been an in-patient. That is often the way it is.)

5) Another "reality obstacle" to making the nursing home decision is often the ill spouse. Frightened, powerless, into emotional denial, often demented to at least some degree (sometimes having to do with judgment), the ill spouse resists the nursing home decision.

"Even ill spouses who are in emotionally healthy marriages," says Dr.

Brennan, “might have had a deficit of care and protection in the family they grew up in, so that when they become ill, they try to claim it back -- from their well spouses.” “Please promise you’ll never send me to a nursing home”, they might plead, often using physical or psychological manipulation or even violence, and sometimes instituting what I call “hair-brained schemes.” I often wonder how a well spouse can feel loved when she hear such a “plea”, which carries along with it the unspoken “Please do nights, lifting, and toilet on me for the rest of my life.”

My own husband and two of his friends believed, seven years ago, that our “non-long-term care insurance” policy would pay for long-term care, in the form of a “night nurse.” They wanted to believe that the only reason he needed to be in a nursing home was that I was being kept awake nights, and that therefore the “night nurse” would completely solve the problem. In a manner somewhat less passive than passive-aggressive, they made countless phone calls, to separate departments of our insurance company, not taking no for an answer. (And in fact, unfortunately, not always being *given* no for an answer, not literally; sometimes, somehow, the people answering the phone would say they didn’t know, they’d try to find out and get back to them. This seems to me like another form of the conspiracy of silence.) This went on for several weeks, until I finally took his two friends aside and told them, calmly and more clearly than I had before, “Look, even if you do succeed in getting a night nurse, I still don’t want him living home any longer.” (I told them briefly how un-helpful previous “night nurses” had been, as well as how days were also untenable for me.)

In an earlier essay I told how Joan’s husband tried an even hairier-brained scheme. Despite advice to the contrary from health-care workers and the intake department at the nursing home Joan was considering, John (in a last-ditch attempt to avoid nursing home, and the fact of the seriousness of his illness) decided that he was a candidate for independent living. If his wife was no longer willing to care for him at home, he’d just move out. He can barely talk, has trouble swallowing, and is basically quadriplegic, but he found a therapist -- There’s always at least one, and that’s all John needed.. -- who not only agreed with him, but who had her own needs, agendas, and detachment from reality which were somehow served by her finding an apartment for John, along with various home health aides. Something I didn’t mention in that previous essay is, he also convinced John who had, remember, dementia (combined with understandable fears) that Joan was his enemy; she brought lawyers into the situation, causing Joan considerable trouble and anguish. Two weeks (and \$9,000) later, the home health aides and other people involved turned out to be irresponsible and undesirable druggies, and John was back home, tail between his legs but still fighting Joan with respect to her nursing home decision. Moreover, their younger daughter, aged 18, is having a lot of psychological problems with all this, and so far she is very angry at her mother for wanting to “put” her father in a nursing home. So Joan is in danger of losing her children, not only her spouse. She is not

at all indecisive about her nursing home decision, extremely ready to move on in her life, but reality is causing a delay very much unwanted by her.

6) An oft-cited (or un-cited) reason for delaying the nursing home decision is “culture”. This one’s a biggie. It includes family, friends, the media, various systems -- especially the health care system -- all part of the biggest biggie of all, namely society. Perhaps “attitude” is a good almost-synonym for “culture”. And society’s attitude seems not to be one that encourages well spouses and at home caregivers to identify and act upon “nursing home time.” “People think it’s shameful to take this person and put him in a nursing home,” says Norma. “They think the family should try to keep him home as long as possible, no matter how miserable that makes everybody.”

In her book, “Music to Move the Stars”, Jane Hawking, ex-wife of the famous Stephen Hawking, writes (p, 311) how, at a time when things for her were beginning to attain “dire straits” proportions, her mother-in-law suddenly, out of the blue, “announced fiercely, ‘You do know, don’t you, that Father will never allow Stephen to be put into a residential home?’” So saying, she stood up, turned on her heel and marched into the house.” Jane had, in fact, not been close to even thinking about “residential homes”, only getting at-home nursing care to relieve her and her children, care which a colleague had offered to pay for and which Steven was refusing. On the previous page Jane Hawking remarks, “The merest hint of dissatisfaction with our situation was quickly identified as disloyalty to Stephen and summarily dismissed with the implication that it was a symptom of my own inadequacy,” and later, “I knew well enough that Stephen’s determination was his defense against the illness but I did not understand why he had to use it as a weapon against his family.” She goes on to describe the manipulations that Steven’s parents used to veto the idea of getting any relief for Jane. For example, Steven’s mother, at one point, “shared in Stephen’s care for much of the time, sometimes feeding him his meals, helping to dress him and sitting by him on the path above the beach so that I could play with the children on the sands below and bathe in the sea. . . I was grateful but I smiled quizzically at some of the remarks she made. ‘Looking after Stephen is not really that difficult, you know,’ she observed breezily. Was she implying that my tales of woe had been pure fabrication? ‘Robert [Jane’s and Stephen’s nine-year-old son, at the time] doesn’t seem to mind helping his father at all; in fact, I think it’s good for them both,’ was her next cheerful remark. Had the coolly intellectual workings of her mind failed to grasp my concerns for my elder child?”

Recall the essay on sugar coaters and non-solutions. Our culture is full of both. Too often it fails to call a spade a spade. Here’s another more subtle sugar coater: describing the nursing home decision as “one of the most difficult decisions you’ll ever make.” Why is that a sugar-coater? Answer: For the same reason as calling the patient/ care receiver a “loved one.” Both phrases buy into

the idea (whether true or false, in any particular case) that the care giver loves the care receiver, and has been caregiving and *is now making the nursing home decision out of love* (and choice). Again, this is not always the case, and the caregiver should not be made to feel that it *should* be the case.

Also, putting someone in a nursing home involves guilt feelings – understandable, and not surprising, given our environment; thus saying “It was a DIFFICULT decision” seems a euphemism that attempts to assuage those guilt feelings. “Difficult decision”, in some people’s mindsets, implies suffering, and suffering means not guilty. The flip side to this, of course, is the implication that that if the care giver doesn’t feel that way – if she isn’t suffering -- then she’s guilty.

Recall the essay on care giving as a woman’s Issue. Our culture is not the best atmosphere for the ending of oppression to propagate in. Celia, a well spouse, talks about “the Italian family syndrome. There’s also “the Jewish mother”, and the Jewish spouse, as well as “the strong Polish, or German, woman”. Norma summarizes the situation when she remarks, “It’s EVERYBODY’S culture. There are just different versions of it.” It’s too bad that society is so full of incorrect and destructive attitudes concerning irresponsibility, selfishness, self-pity, complaining, etc., and that it so often makes the lives of its individuals miserable, to no good end.

“Is it nursing home time yet?” is a question that I actually asked of health care professionals when my husband was still living at home and I was still doing “nights, lifting, and toilet”. The answer was usually a shrug, or silence. The answer was never “yes”. It wasn’t until Jeff was actually living in the nursing home that I got enough real answers; then suddenly everybody was quite clear. “You’re the hero of the floor,” I was told, by several people at Inglis House, including the head nurse. “We can’t believe you took care of him all these years.” Yet, during “all these years,” other professionals had witnessed my “taking care of him.” and not particularly noticed or remarked on my “heroism”, let alone recommend nursing home. Huh? I thought then. Huh? I think now.

7) This is about the more subtle emotional and psychological factors, on the part of the well spouse, which delay or prevent nursing home placement. When I was promoting “Dirty Details”, I was often asked, “Why did you keep doing it for so long?”

I’d smirk, slightly chagrined. Indeed, it seemed I had only *partially* answered that question in “Dirty Details”. I had described the feelings of alienation and hesitancy -- and the “conspiracy of silence” -- on the part of society, and the health care system. I had also described the failure of the health care system to

even begin to point me (and many other well spouses) in the right direction, namely the nursing home, and to give me some idea as to “where I stood.” I thought that had explained why I kept “doing it for so long.”

Looking back, it now feels (I say this at the risk of seeming paranoid, which I definitely am not.) as though somehow, subtly and indirectly, the entire health care system -- the medical schools, nursing schools, social-worker schools as well as the working environments and policies that follow -- has been set up so that health-care workers at all levels and in all positions try (at a subconscious level, perhaps) to keep ill people out of nursing homes, and in their own “homes”, being cared for mostly by family members (instead of informing and, when indicated, advising these family members). Again at the risk of seeming paranoid, I think how this saves the state money and at the same time upholds our “culture”, just described.

Is there any connection between the two? Is everyone in cahoots? I make no accusations, develop no theories: I merely ask these questions: And when I asked the question at Border’s readings, I got a lot of body language from people in the audience. Also, a friend from my choral group told me, “You saved the state a LOT of money. You were a cheap date.” When I think about this now, it hurts and makes me angry.

Perhaps this brings us back to the “Care Giving as a Women’s Issue” essay, especially the part about abuse. And perhaps the bottom line answer (as well as the bottom line of this chapter!) to the question “Why did you do it for so long?” is: “Well, it ALWAYS takes ‘so long’ for an abused person to realize she’s abused.”

“THE SEX WORKSHOP”

Approximately ten years ago Deborah Hayden began editing an “Anonymous Survey” for the Well Spouse Foundation newsletter. Each issue dealt with a different question, about an aspect of the well spouse condition, and subscribers were invited to send in responses to the question. These responses would be published anonymously, with the obvious advantage that people could feel free to write anything they wanted, without fear of shame or repercussion. (Granted, people are inhibited or into denial, even with respect to admitting things only to themselves, but less so than if they had to own up to it to others.)

That column is still continuing (with a succession of others editing it), with “heavy-duty” topics such as anger, abuse, how the kids are doing, and why do you stay in the marriage? But the very first (and several times repeated) topic was sex and intimacy. The question was worded something like this: “How do you reconcile the human need for intimacy with marriage to someone who might not be able to entirely provide it?” Here are some anonymous quotes from that first column:

“I miss being touched. My husband has recently lost feeling and dexterity in his one ‘good’ hand. He has severe chronic pain in his genitals, and he has a tube that smells offensive to me. I miss being sexually attracted to him and feeling like I’m a sexual being. We love each other deeply and often kiss and hug, but I’ve actually felt repulsed some of the time he’s tried to kiss me sexually. He hasn’t been sexual for so long because he’s in such pain. I’ve lost desire for him...”

“He hurts. I soothe. He complains. I listen. He is hungry. I feed... I nurture. He receives. I miss talking, really talking and sharing... If I ever become a widow, I’ll never look for another husband...”

“We have the intimacy of a bond of hate that can’t be broken.”

Around the same time that Deborah Hayden did that column, she also ran a “sex survey.” One of the questions asked was “Do you have a reasonably satisfying sexual relationship with your ill spouse?” Out of the 150-odd responses, only two were “yes”. Here’s more from one of the “repeat sex-forums.”

“Intimacy? There is none. My spouse wants it. I don’t. With the bills, the kids, my work, the chores, I’m too busy, too tired, too angry. The responsibility has robbed me of life’s enjoyment.”

“For many years we were able to maintain a fairly healthy interaction as a couple. But then the losses began to mount -- from a cane to a walker to a

wheelchair ... these impediments did not deter intimacy completely -- a whispered word, a caress, a hug. Then came incontinence, and I must admit that this aspect of the disease blunted our sex life. I found it difficult to be romantic lying on rubber sheets. But the biggest blow of all was the brain damage.”

“Because the care giving has gone on for so long, I can hardly remember the intimacy. I don’t think I’d know how to go about having it any more. I can’t even imagine being interested.”

In “Music to Move the Stars” Jane Hawking, Stephen Hawking’s ex-wife, writes [p. 328], “It was becoming very difficult -- unnatural, even -- to feel desire for someone with the body of a Holocaust victim and the undeniable needs of an infant. Certainly one could admire and venerate the intellect, but the intellect had no arms in which to hold me, no physical strength with which to bring me the comfort for which I yearned. I clutched at the intellectual bond between us for whatever reassurance it could bring, but I foresaw that the marital relationship was inexorably drawing us on to dangerous psychological quicksands which threatened to suck us down, perhaps to sudden death for Stephen and long-term insanity for me.”

Later in the book she tells of advice which she was lucky enough to receive from friends and colleagues: From one of her husband’s doctors, “you should make a life of your own”. From Stephens’ colleague Bill Loveless, “You are just as important to God as Stephen is.” And, once she found a platonic but loving relationship (which eventually ended in marriage), from her brother Chris, “You have been steering your little boat single-handedly across a very stormy, uncharted sea for many years. . . If there is someone at hand, willing to come on board and guide that boat into a safe harbour, you should accept whatever help he can offer.”

After a while TAKE CARE!, the newsletter of the National Family Care Givers Association, also ran an anonymous “sex column.” Here are some excerpts:

“It’s not the actual act in itself that I miss. What I long for sometimes is a healthy male body against mine in a standing position. Someone to literally lean on and to embrace me with strength...”

“I do everything for him all day long and don’t want to have to initiate that, too...”

“Most of the work is done by me.... Afterwards it’s back to the duties of the caregiver...”

“I have to help to put her arms around me for a hug...”

“... I handle abstinence one day at a time. It's no more a problem than if he were on a business trip or temporarily ill or injured, as long as I refrain from wallowing in thoughts of 'Never more! Never more!' I also find it wise to avoid romantic stimulation such as some music, novels, certain TV programs, or romantic daydreams...”

-- To give up even your dreams? Is this any way to live? The anonymous letters have also contained a smattering of positive things, but remember, these represent only ONE point in time, they are quite individualized, and I know from sustained friendships and contact with other well spouses that these small remnants of good sex and intimacy wear thin after a while or disappear completely as physical reality and brain damage progress. Here, nonetheless, are some of the more positive feelings that well spouses have expressed about sex or intimacy with their ill spouses:

“My children are angry that I will not give up the task of bathing my spouse. It is physically difficult, but it is the only time of the day I feel focused enough that we can be intimate. The other day while we were in the roll-in shower, I was washing his hair with my fingertips, neither of us yet speaking. Then I heard 'This is almost better than sex.’”

“We have great memories of the excitement associated with sexual intercourse...”

“It's a shame that [oral sex] is getting such a bad rap... it's a satisfying alternative when intercourse is not an option...”

Some of the letters also contain info on partial solutions to the problem:

“I gave myself a romantic affair. It is respite and helps resolve many needs. It's a sharing of some positives in life... an escape to taste what's been missing. laughs and more. Maybe it has brought fantasy more toward reality. This has given me a glimpse [that] I can be more than I've been...”

“I've been having an affair with another well spouse who lives out of town... we both told our spouses before we began. My husband accepts this, although it's quite painful for him. It got easier once he realized that I still love him and am not leaving him. His acceptance is quite an act of love and makes me love him more. I'm so happy to be sexually active again. I can't believe I've denied this wonderful part of myself for so many years.”

“I have a close friend who has also been a lover... and he helped with the care giving... but it was also a secret, which takes a gradual toll on any relation-

ship.... I have recently started to go out with another person. He has been a care giver as well and understands better than anyone else I have met. I feel totally different about this relationship. I am optimistic again.... I desperately need this kind of support and refuse to feel guilty about the fact that I am married but still need intimacy elsewhere..."

"My psychologist suggested I should try to masturbate..."

"My son set me up with someone, single, he had known for a long time... It made my headaches go away... I set the rules: do not get emotionally involved, or feel like a teenager, or fall head over heels. It might feel like you are using the person, but we both went into it with all the cards on the table..."

"Can I say I had an affair if it wasn't sexual? The physical attraction and intentions were obvious and well-conveyed, even if not by touch. The interaction was thrilling, the connection palpable... I actually felt better about my situation."

"I have a friend with whom I have conversations where the discussions involved topics that have depth and passionate feelings. There is no physical relationship and yet I consider this one of the most intimate, loving relationships I've ever had. It refills my soul with love which I give [to my spouse] in my care giving. I had to ALLOW [underlining mine] myself the privilege to enter into this friendship, therefore it bordered on being a 'traitor' to my once very intimate marriage partnership... Once I let this new intimacy into my life, I had a rebirth of loving feelings..."

Anyone who regularly attends the annual Well Spouse Convention will hear this echoed by many well spouses, and each year we get updated "sex sagas," especially if we attend what's come to be called "the sex workshop."

In October of 1991, at the third Well Spouse Foundation Annual convention held in Pottstown, PA, one of the best attended workshops was what was described in the brochure as the "Relationships Workshop." No one knew this would happen, but it turned out that more people wanted to talk, not so much about their relationships with their ill spouses, but about speculations regarding relationships outside the marriage.

Most of us weren't having any, or were and didn't reveal it, but obviously most had thought about it, and seriously considered it. A few had tried it once or twice and had not found it satisfactory enough to continue, for various reasons. That workshop was very emotionally charged; I remember one woman crying, upon learning that her good friend would have had extra-marital sex if she had the opportunity. When the hour and a half was officially over, several people retreated to another room, to talk some more, and a continuation of the workshop

was informally planned (and well attended) for later that evening.

By the next morning the workshop had already had its affects. Of the close friends I had made at the conference, one confided that she and a man she had met, had gone for a walk, begun to develop a closeness, and were planning to meet for a weekend together in a couple of weeks. "I'm looking forward to it," she said. Another friend stopped at my table to bend down and whisper, giggling, "Last night I had a you-know-what."

A tradition had been set. Every Well Spouse Annual convention now includes a "Relationships Workshop." At least so it says on the program. But everyone present or in the know calls it "The Sex Workshop" -- and woe betide any workshop running concurrent with it. The number of "well spouse couples" has increased manifold since that first "sex work shop", and the couples are less and less secretive.

My friend and her well spouse lover stayed together for close to ten years. They loved each other deeply. My friend also loved her husband deeply. When she talked with me about either one, I could sense much tenderness. Her ill husband, who was ill when she meet him and with whom she has never had intercourse, knows about her lover. Life does strange things; my friend would never have guessed that she would be a "bigamist", seriously committed to and working hard on two meaningful relationships.

From the start, I was concerned and worried that the Well Spouse Foundation -- or at least the small sub-community consisting of those who regularly attend the annual convention and who know one another well -- would become a "couples affair," that there would be pressure to couple up, and that those who were UNcoupled would feel or actually be left out. But that has not happened. Well Spouse couples are NOT clique-ish at the Convention, and they seem to make a special effort to show that, at conferences, the well spouse community comes first. In fact, at conferences my friend has often confided to me, "I don't WANT TO sit [at dinner] with Harry; I want to sit with you and Norma."

It seems to me that a large part of the well spouse community has taken a stand. Although this stand is not official, it's the *beginning* of something official. The "sex workshops" are continuing, not only at the annual Conventions, but at the smaller, more local, "getaways" such as Split Rock PA in May. A few years ago, at the "sex workshop," my friend stood up and, as she put it, "Harry and I came out of the closet." That is, they announced their relationship. They stood up and said, not I WOULD LIKE to have a relationship" but "WE ARE HAVING A RELATIONSHIP"

And now, at every convention's Saturday night, there is dancing. Each well spouse can make what she/he wants of it. We can choose not to attend, to go off on our own, take walks, do something in town, visit individually with friends in our rooms, or go to bed early. Or we can actually attend but merely watch the dancing. Or we can take part only in the group dances (of which there are specifically many). Or we can go and dance with same-gender friends. Or we can go full blown, as we did when we were single, and find out who asks us to dance and how seriously.

For a long time I chose to take part in the group dances, with perhaps a friendly dance or two with an individual of either gender. From year to year I noticed that, on some level, I tended to evaluate the "progress" I was making (in "moving on") by how I felt at those dances; I noticed that with each passing year attending the dances felt more and more right.

But what I noticed even more strongly is how **MOVED** I always felt as I watched the other well spouses dancing. I thought about "nights, lifting, and toilet" and the other "dirty details" of their lives, and then I'd see their arms waving, bodies wriggling, shouts and laughter. The contrast between that laughter and "nights, lifting, and toilet" is moving. I saw Betty, 25, husband with an incurable spine disease, three-year-old daughter, the last they will have together -- I see her kicking and letting go. I saw Jim -- married four years, no children, no possibility of children, not happy -- I saw and felt his wild and well-earned abandon. I felt the needs, the deprivations, and the capacity for joy. I felt, for sure, the human spirit.

I felt especially happy for the couples. I knew that my friend's husband was often beset by pain, pain which she was powerless to heal, and I knew that Hospice had dropped them several years before because he did not die, and then I watched her and her lover, hand in hand, running with the crowd. I was so glad that they had this chance, this evening, to have a "regular" good time, to do what so many non-well-spouses do, to be a member of the healthy human race.

And now I show up at well spouse dances with my new love. I'm not the only well spouse, or former well spouse, to do so. No one bats an eyelash, no one is judgmental; in fact, everyone is happy for us. The dances, to me, represent something. Not only hope for the future, but a reminder that we are all, in the *present*, not only well spouses, but well, period. And that we are, or can be, other things besides caregivers. The mere existence of these dances, even for those who choose not to go, gives us that message; that mere existence helps bring us back to our senses, back to our lives.

WANTING OUT, GETTING OUT

Several years ago, at a Well Spouse Association annual convention, Fern Zeigler stood up and announced a “spontaneous” Separation and Divorce workshop. Fern herself was not at all interested in separation or divorce for herself, nor even nursing home. She was, at the time, still very much in love and wanting to continue to live with her husband, who was a wheelchair user when they met 20 years ago and was only later diagnosed with N. S., a chronic progressive incurable, and often painful, disease involving benign growths on the spinal column. Fern had genuinely chosen to stay with her husband indefinitely; she was not denying anything -- anger, resentment, etc. However, being a thinking person and a social worker sensitive to the lives and needs of all well spouses, Fern recognized that, for many well spouses (even if not for herself) a point is eventually reached when no amount of respite is enough, and when they cease to feel, or want to feel, married.

Fern announced a time and place for the Separation and Divorce workshop, and so great was the interest that, at dinner that evening, a special, and spontaneous, Separation and Divorce *table* was set up, indicating, among other things, that the workshop of the same title and content would indeed take place.

Fern did not herself attend that workshop. But twenty-odd other well spouses, including me, did. In the back half of a rather long room we arranged chairs in a circle and began. All of us were well spouses who wanted out. Two or three were close to getting out; they had filed for divorce. The vast majority were nowhere near that point. Many were in abusive relationships, knew it, wanted out, and their presence at the workshop indicated that they were at least thinking in that direction. Their contributions to the workshop made this even clearer. “The way my life is now, I really don’t see any reason to get up in the morning.” “Suicide is an option; divorce is better.” “What I really want is to get my life back.”

Practical concerns, hesitations, and fears were also expressed -- logistics such as “Who would take care of him?”, financial questions such as “What would I live on?”, caregiver marital loyalty (The word “abandonment” came up several times.), and family and societal judgment. In fact, Jody Smith (who was at the time at the tail end of divorce proceedings) commented, “Even in the well spouse community, I feel I’ll be frowned upon.” And indeed, at the time the former Well Spouse Group did consist solely of the widowed, no divorced or separated. These widowed, however, do not always seem very sad; in fact, they often smilingly refer to themselves as “graduates,” and are to some extent the envy of many well spouses at the conventions. In fact, a commonly expressed sentiment has been “I can’t wait to be a graduate!”.

In some sense, the Separation and Divorce workshop seemed tellingly familiar. I recognized the hesitations expressed, and the agonizing -- the same hesitations and agonizing that I had felt during that year of deciding that my spouse had to live in a nursing home. Indeed, many of the comments made were all too similar to the kinds of things described by well spouses in the process of making the nursing home decision. Perhaps John Fischer hit the nail on the head when he remarked, "Inertia is a very powerful force." So, I would add, is fatigue.

Some of us described a kind of reverse guilt-feeling -- that is, not guilt about divorce- thoughts but the opposite, guilt about not being divorced *yet*. "My conscience is nudging me, 'It's time to get out,' someone said, and someone else offered bitterly, "I have BOTH guilts."

Most care giver literature and workshops seem to focus on support and admiration for the caregiver *because* she's a caregiver. The attitude seems to be "You're doing a wonderful job." (How hypocritical! How can anyone know what kind of job we're doing? Does anyone come into our homes and observe?) Again, the attitude is "You're doing a wonderful job; KEEP UP the good work." (The answer which that workshop would have given is "No thanks!") Indeed, what many caregiver advocates seem to believe is that we should be supported *in our role*. And I wonder to what extent the support and admiration would continue if we decided to refuse that role.

Caregiver newsletters often print "A Care Giver's Bill of Rights." To me caregivers' rights are a special case of citizens' rights, or of workers' rights, and I would include some specific Amendments, such as the right to a night's -- or a day's -- sleep, the right to an eight hour day, the right to be paid and, finally, the right to quit. Shouldn't advocating for caregivers mean offering, to the extent that reality allows, the right to quit? (In the final "Suggestions" chapter, more detailed ideas will be offered as to how to incorporate this spirit into our health care system.)

There have since been further Separation and Divorce workshops. As Lilly Cohen (a Well Spouse Foundation board member and activist) has happily observed, in a Well Spouse Association mailing, "The Well Spouse Association has evolved to a point that we don't see ourselves as martyrs, but as having choices." Indeed, *becoming* a well spouse in the first place is certainly not a choice. But what about *staying* with our ill spouses, eventually (or immediately) becoming caregivers, doing "nights, lifting, and toilet," living in "dire straits" -- were all those choices? If so, were they *informed* choices? More importantly, were they *free* choices? To what extent were the choices truly ours -- and not our ill spouses', our families', society's, and so on?

Moreover, do we *continue* to make these choices? As conditions change,

and/ or as time passes, causing our feelings and stamina to change, do we have the right to change our minds? Are our minds allowed to grow, or are they supposed to die? When we “made” the “choice”, did we make it for all time?

As in marriage *without* chronic illness, there might come, or might have already come, a point when we don't want (nor is it advisable to want) to stay in the marriage. As the Well Spouse Foundation newsletter puts it, “do well spouses have the same divorce rights as other citizens?” And as someone at the above-described Separation and Divorce workshop asked, “‘Til death do us part’ -- but what about death of the MARRIAGE?”

Even supposing that, like my friend Fern, we keep electing to stay with our original decision, still, our choices mean more when (like Fern) we continue to re-evaluate, and re-choose. Like renewing marital vows (like, for that matter, renewing magazine subscriptions), it both reflects and affects our relationships and our behavior -- and it also keeps everyone on his toes.

MAINSTAY, the Well Spouse Association's newsletter (named after Maggie Strong's book), has an ongoing column called “Forum;” each issue explores a different well spouse related question, to which readers are invited to respond; the answers are printed anonymously. A recent “Forum” was on “Why do you stay?” The answers contained an ambivalent mixture of love and bitter-ness. “Genuine caring, love, guilt, fear,…” summarized one writer. Others focused more on the guilt and fears, and uncertainties. “I'm afraid of what people would say.” “I'm afraid of being lonely.” “Where would I go and how would I support myself?” “Probably because my father physically pounded into me that I make my own bed and I sleep in it.” (My own question: WE make that bed?) “I think it would break my heart to leave her.” “Because of vows.” “Someone has to do it [meaning the caregiving].” “I don't know how to leave.” And just plain “I don't know.”

Young marrieds just starting out, fresh out of high school or college or another relationship, often operate under conditions provoking thoughts like the above. But they aren't as tired. Nor as burdened. Nor as invisible. Perhaps one of the more poetic anonymous answers to “Why do you stay?” will shed some light: “Another word for chronic is boring... I have become slowly paralyzed... along with him.” And perhaps chronic illness leads to chronic indecision -- inertia runs rampant.

I would like to respond to some of the above sad statements and questions, as well as to the original question “Why do you stay?” I'd like to add another question, “SHOULD you stay?” The answer to that new question is often yes, though sometimes *temporarily* yes, but in this society it's very difficult to identify and admit when the answer is no. Thus that question (about staying in *anything*), when it enters one's life, needs to be given very serious and perhaps difficult

thought.

Although many well spouses stay, temporarily or permanently, for honest, healthy, and loving reasons, It also seems as though many of the above comments express one or both of two phenomena: (1) fear and (2) lack of information. (Perhaps, even, the first is a result, or partial result, of the second.) For example, "I'm afraid of what people would say." Obviously, some people will say things to be afraid of (and/or indignant about) and other people will be supportive. One could put out feelers (say to others, for example, "I SOMETimes THINK about leaving") and get some idea of what the people will say. One could also seek out friends and associates, especially other well spouses, who will say supportive things; one could also go into therapy, with a therapist versed in chronic illness issues.

"I'm afraid of being lonely." Actually, the writer who said that added that s/he was lonely *now*. Also, one could begin to find out just how lonely one will be, by noting how one feels when alone. One could also cultivate new and already existing friendships, friendships which will combat loneliness. Or, on a more activist or alternative lifestyle level, well spouses who choose to divorce or separate could form households together.

"Where would I go? How would I support myself?" One could begin to research this; in particular, talk with a lawyer. (Well spouses have to do that, anyway, at one point or another, for end-of-life issues)

"I think it would break my heart to leave her." Yes, it will hurt, in some way. So would staying. But also, leaving (so I have heard and experienced) can do wonderful things for the heart, things that mend rather than break.

Here are some other thoughts:

1) About "genuine love:" Be honest with yourself. How truly "genuine" is it -- and how strong? Also, how long will it continue to be genuine and strong? And remember, the answer to that question does not depend only on you, but also on your ill spouse, and on the disease -- how its escalation has affected and will affect marital conditions. If the love is no longer, or never was, "genuine", that's not necessarily your fault.

2) About "I make my own bed and I sleep in it " -- no way! Even if you did indeed "make your own bed" (rather than society, or the family, or nature), you do not, for that reason, alone, have to "sleep in it." The laws allow people to change their minds, and their beds -- and to not be "punished" forever for making the wrong bed.

3) About “someone has to do it:” Yes, and you’ve already taken your turn, by a long shot.

It isn’t only separation and divorce that are on many well spouses’ minds. Some ill spouses are so ill that they are probably, or apparently, close to death (“the D-word”, as the authors of “Liberating Losses” put it). I say “probably” and “apparently” because in the case of chronic illness, one can never tell. Fern’s husband was on Hospice for almost four years. (They finally took him off, complicating their lives horribly. Hospice is technically for people who have less than six months to live. Many people, so I heard at a bereavement conference, “fail Hospice”!) The doctors gave Emma’s husband several weeks tops; he lived ten years with a brain tumor that caused him to be both verbally and physically abusive.

As with any illness (chronic or not) there’s suffering if not pain, and as in any fatal illness part of us hopes for a relatively quick and easy death. As the years and decades pass, that part of us often grows larger. We hope for the ill spouses’ sakes, and some of us admit hoping for our own sakes. *We* are suffering, too. And we are certainly tired. And, perhaps, bored. Remember Anonymous in the newsletter Forum, “Another word for chronic is boring.” In other words, enough already.

At this point, under these conditions, separation (or rather, further separation) or divorce would be extremely hurtful for the ill spouse, highly impractical (in particular financially), and very possibly not necessary. So the kind of “out” on many well spouses’ minds is death. Indeed, one of the nightmares of chronic illness is that, very often, as the years pass, the spouse and family of the ill person have already grieved, have already (in various metaphoric ways) said good-bye, perhaps have even reached the acceptance stage of grief. But the ill person is still around. And *his* grieving process might be proceeding quite differently.

He might be relieved to still be alive, afraid of dying, or simply quite willing to keep the status quo. He of course is in quite a different position, viewing matters from a completely different window. And he certainly has nothing to gain by separation or divorce. If, like my late husband for many years, he continues to lead some semblance of a productive life, he is often admired by friends and health care workers. “Amazing,” “courageous,” etc. but what is the well spouse supposed to do and feel? Isn’t she also “amazing” and “courageous”? And for how much longer should and can she continue to be?

In their bereavement workshops, the authors of “Liberating Losses” ask the question, “What DON’T you miss about the person you’re grieving?” Being open to answering this question gives griever (traditional and non-traditional) permis-

sion to not deify the dead person; it allows them to realize that not missing everything about that person is not tantamount to not missing the person at all, and that not *grieving* everything is not tantamount to not grieving at all. This can nip a lot of guilt feelings in the bud.

In the case of some former well spouses -- that is, the widows of chronically ill spouses -- there can be a lot that we don't miss. Do we miss nights, lifting, and toilet? Do we miss living in dire straits? Do we miss being in such social limbo? Of course not. In fact, there might be so many things we don't miss that it *is* tantamount to not missing the person at all, to not grieving at all.

So if a well spouse allows himself to anticipate or fantasize his ill spouse's death, the 'anticipatory grief' might not be *traditional* anticipatory grief. In fact, it might be anticipatory *relief* or even anticipatory *rejoicing*. In other words, to put it mildly, the well spouse is often very emotionally ready for the death of the ill spouse.

The scenario varies from person to person, family to family, situation to situation, but the above-described phenomenon, with the timetables of the ill and the well spouse so out of synch, is quite common, if not always acknowledged. Even Fern, who still fully loved her husband and chose to live with and care for him, used to say, "A part of me is looking forward to when he dies -- all the things I'll do." (She also used to say, "A part of me is afraid I won't do ANYTHING." In actuality, he died several years ago and she has done plenty!) And Tom emails from Canada, in the midst of what seems like his wife's last hospitalization (after a marriage of many decades, only two years of which he was not a well spouse): "I am still hoping that my wife's death will not be too long in coming. . . I am finding it hard to watch and to know there's little I can do." And Andrea, who had made decisions similar to Fern, for similar reasons, eventually asked Hospice for morphine and, the night he died, whispered to herself, "Please let this be it. I couldn't go through this again." And Sarah, interviewed in the first chapter on "What Care Givers Do", says, "I'll be young again when he dies." And health-care professionals with savvy, like Sister Patrice who worked with and advocates for well spouses and family members, joining us at the Well Spouse Convention every year, tells us, "Don't call 911."

In *Dirty Details* I related a conversation between Norma and a worker in her husband's nursing home. Norma's husband had begun a special physical therapy routine and Norma, in an unguarded moment, had blurted out to a health care worker, "it won't work, will it?" She had then gasped, ashamed of her reaction. But the health care worker understood -- understood that what her question manifested was fear, not hope, that she didn't WANT it to work, didn't want to go through any more, didn't want anything that would prolong or complicate the whole thing.

I also related how Norma and I often talked, and laughed in familiarity and friendship, about this very same phenomenon. Since the publication of *Dirty Details*, our jokes have become even more pointed; in plain language, **WE WANTED OUR SPOUSES TO DIE.**

The nursing home would call Norma; “come right over; this could be it...”

“Well?” I’d ask.

“He pulled out of it, darn it.” -- and we’d laugh, yes laugh.

Only well spouses can talk and joke with each other like that. Only well spouses have that rapport. (And what well spouses jokingly term “civilians” often don’t.) Only well spouses understand that there is bitterness in our laughter -- wry-ness, and anxiety. And that yes, there is, if not felt at that moment, sadness. And yes, we feel the discrepancy between what we are saying and the things we said decades ago when we were first dating our now-ill spouses. And yes, we sort-of cannot believe what we are saying now; we are stunned at what life has come to.

Well spouses understand that we have been through so much, so many times over, that we are in some sense, using one well spouse’s phrase, “beyond all that” -- beyond bitterness, beyond grief, beyond being stunned. Our strongest sense right now is that **IT IS TIME FOR IT TO BE OVER.** (Enough already.) Like a broken record (in many places) it is grating on us big-time.

Truth and laughter are what we know now. Norma tells the following “joke” to Fern, Rita, the well spouse support group she coordinates, and the other board members. By now a good portion of the well spouse community, nation-wide, knows about that joke. Norma at the time worked once a week as a chaplain in her husband’s nursing home. One of her duties was to talk with family members whose residents had just died. Every time she does that, she told us, she secretly thinks, “Oi. always a bridesmaid, never a bride!”

Well spouses across the country have laughed at and understood that joke; it is not an aberration, and it is not abnormally cruel or selfish or callous or uncompassionate. It is a shared and inescapable feeling, which needs to be acknowledged more, in particular by health care workers who deal with family members. (In the “Suggestions” chapter, more detail will be given about this, amounting to “Don’t **ASSUME** the family members want the patient to live.”

Two years later I helped form a Well Spouse Separation/Divorce Group. It consists of well spouses who are thinking about, considering, or have actually done, separation or divorce. It's an email group, because well spouses who wanted to join came from all areas of the country. It's truly a support group, as well as a friendship group. In sharing this very private matter, we wound up sharing many other things. Moreover, the group actually helped. More than half of us now actually *are* separated or divorced, and eventually we trusted one another enough to share thoughts of finding new loves, along with the unique obstacles and second thoughts concerning that. Now several of us actually have found new loves, and are leading "civilian" lives in some ways, but are still either haunted by our long ordeals or worried about what our demented and/or abusive ill former spouses might somehow be able to do to ruin our hard-won happiness.

Several years ago Jon and I flew halfway across the country for his translators' conference, which happened to be in the town where a special friend of mine from the Separation/Divorce group lived; we were able to meet face-to-face, and to meet her new love. The four of us had dinner in a great restaurant, and shared and shared and shared. Her situation is very complicated; she married her ill spouse several years ago, in a hurry, despite some red flags, because he has cancer and was given a short time left to live. But he has lived beyond everyone's expectations, and has become abusive and threatening; she is separated, and in love with someone new and kind, but afraid.

Even when well spouses do get out, they still need other well spouses. For it seems to be true that once a well spouse, always a well spouse, or always a former well spouse. Whatever "life lessons" well spouse-hood taught us have stuck, perhaps too much. Like all survivors, we have learned fear and we have learned despair, and we often feel stuck in "survival mode". And, for some of us, all smaller fears and despairs now feel big. As Norma says, "life chipped away at us." Well spouses can never quite get out completely. Once a survivor, always a survivor. Once a veteran, always a veteran. We will never be "civilians" again.

SUGGESTIONS FOR THOSE IN CHARGE

From "Mainstay" (the Well Spouse Association newsletter), Jan/Feb '98, comes a kind of "Well Spouse 101" article, a list of items which citizens, legislators, policy makers and caregiver advocates are urged to be educated about. Here is that (slightly elaborated upon) list:

1) Illness affects all ages. Don't forget young well spouses, often giving birth to and raising children while simultaneously being responsible for caregiving. Debbi's husband was diagnosed with multiple sclerosis when she was pregnant with their second child; my husband fainted off the wheelchair as I was falling asleep for an emergency Cesarean. So concentrating solely on programs for "the elderly", or funding programs "only for age 55 and older" won't quite cut it.

2) Many at-home care givers are simultaneously working outside the home. Obviously, while they're at work, someone else needs to do the caregiving, and hiring someone to do this should not be so costly or inadequate that the caregiver is forced to quit her job. Well spouses have the same right to choose their profession that other citizens have. Antonia Cedrone, a New York psychologist whose husband died over ten years ago from a six-year-long illness that was never definitively diagnosed, says, "Everyone from all the agencies was really surprised when I told them I work. They said they never 'had' any other client where the wife worked." Shrugging, she added, "That's hard to believe, in New York City, but that's what they said."

All the policies and programs offered were geared towards families where there was someone who would stay at home; every single time Antonia dealt with a new agency, adjustments had to be made. National programs for well spouses are also often not geared towards well spouses who are employed. In particular, Medicaid laws don't always protect the incomes earned by well spouses.

3) Well spouses are often in financial "dire straits," and as much as possible needs to be done about that. This includes "affirmative action" such as tax credits (perhaps being exempt from taxes, as are religious entities).

4) Not only does respite care need to be available, but *enough* respite care. 20 hours every six months will not keep a caregiver sane nor make it possible for him to have a vacation. Moreover, offering respite piecemeal -- four hours here, four hours there -- might only complicate matters, and cause a well spouse to decide NOT to go away for the weekend after all.

5) Care givers get emotionally and physically exhausted; doing the work of

an entire team of nurses and doctors takes a lot out of us. Well spouses have the same right to a night's (or a day's) sleep as other human beings. If they don't get it, and they usually don't, there will be not only burnout but loss of mental and physical health. Well spouses cannot and should not (nor, usually, do they really want to) carry a ridiculous portion of the load.

5) Perhaps most important, "what care givers do" needs to be more widely acknowledged throughout our society -- from "nights, lifting, and toilet" to pushing past Emergency Room doors, described in Linda Welsh's "Chronic Illness and the Family", to putting up with abuse, verbal and physical, from demented or partially demented spouses, to dealing with financial dire straits and the enforced neglect of children. None of the above seems constitutional. All seems like cruel and unusual punishment. Society owes us bigtime.

I would add a few more points to the list, some of them borrowed from the "Sugar Coaters" chapter of this book:

6) Caregivers do not necessarily love their care receivers. (And the patients are not always "loved ones".) That care givers love their care receivers should not be taken as a given, especially at meetings between health care professionals and family members.

7) Care givers are not martyrs (even if they say or act as though they are). In fact, many caregivers, if asked and pursued, will admit to not wanting to be caregivers in the first place. From ROUGH CROSSINGS, p. 31: "While it is understandable that heroic families are praised, public policy should not be based on an expectation of martyrdom."

Since all of this amounts to no less (and lots more) than the breaking of the "conspiracy of silence", it is a tall order for this society. Moreover, society and government are also not God. There are logistics involved on both sides, and the situation is not always simple. However, education goes a long way. One course in "Well Spouse 101" will change attitudes, and attitudes propagate, into, eventually, change in procedures and policies. Before long we're into "Well Spouse 102"!

Keeping all this in mind, this chapter presents some concrete ideas on how society, especially those in charge of society, or in charge of parts of society, can work toward making real change. The suggestions of this chapter are gleaned from readings, thinking, and conversations with other well spouses, and health care workers. They fall into several categories; suggestions for health care workers (both professional and non-professional), policy makers (in hospitals, nursing homes, home health agencies, and insurance companies), legislators, friends and relatives of well spouses, and of society in general. (It goes without

saying that this chapter is NOT about suggestions for CAREGIVERS! This is not a “how to cope” book.)

Keep in mind that these suggestions are colored by (but do not depend for their existence or validity on) my personal (and political) belief that our health care system must, if well spouses and care givers are to be equal citizens of this world, be such that family members of chronically ill people have the choice whether or not to become care givers, and to continually have the privilege of discontinuing this choice. This attitude must be actively upheld in the sense that family members are presented with this option to “quit”, without penalty and in a convenient setting, in all dealings with the health care system (for example, meetings with social workers and discussions with doctors).

From ROUGH CROSSINGS, p. 44: “Family caregiving is a dynamic role. Transitions in the care recipient’s condition, care setting, family structure, or financial status, or the primary family caregiver’s health [mental and emotional as well as physical] may all be occasions to re-evaluate the care plan. At some point the primary caregiver may no longer be able to provide care. . . an appropriate transition should be arranged.”

That is, it is imperative that it not be automatically assumed that a given family member will become or remain a caregiver. There is no law that says she has to be, but there seem to be laws and traditions that inflict penalty, stigma, and harassment on such a family member who doesn’t choose to.) Nor should it be assumed that the family member will do each of any of the smaller duties that need to be done. “During the last hospital stay,” says Tonya Whyte, a high-school mathematics teacher from Vassar, Michigan, whose husband was diagnosed with multiple sclerosis six and a half years ago, “they mentioned that a daily catheter might be needed. He said he didn’t know if he could do it and the doctor said, ‘We will teach your wife.’ No one asked me if this was something that I would want to do. They just assumed. Everyone assumes.”

Yes, there are practical difficulties with the ideas involved here, and the health care system is not always “set up for it”. But this is one of the things to shoot for; reality is eventually affected by dreams, and by consciousness-raising (even if it takes a generation, or a revolution, or two). That said, we list some suggestions for individual health care workers -- suggestions that do *not* depend on what the system is doing; if you’ve a health care worker, you can incorporate these ideas in your job *tomorrow!*

Here are suggestions for doctors, nurses, and other hospital personell:

(1) Re-read the chapter on sugar-coaters and non-solutions, and then watch your language!

(2) Don't automatically assume that caregivers want their ill family member to live as long as possible. For example, when you give us "bad" news, we might, at least in part, consider it GOOD news.

(3) Keep your ears perked for info about helpful resources (in finding help with caregiving) and then share that info with any family members you encounter. (And please don't share wild goose chases -- that is, seeming info or phone numbers that won't lead anywhere. Keep in mind that, at least in the experience of the many well spouses I have known, *most* info is in this category. In fact, try to research this info yourself before presenting it to family members.)

(4) When the ill spouse is in the hospital, don't expect too many visits from family members. Know that for them this is a break -- possibly the *ONLY* break they'll get -- from care giving. This means they finally get a chance to sleep, re-connect with the other people in their lives (for example, children), and re-charge. Perhaps you can even gauge the body language (and verbal language) of the family member and then say things to encourage her to "go out for dinner -- He'll be fine here."

5) Along that same vein, don't expect (or even ask) family members to help with the patient's care.

6) In general, note the condition of the patient and the type and degree of care that he needs, and realize what this says about the usual everyday life of the family members (that is, when the patient is not in the hospital). Use your imaginations to figure out "our story", as psychologist and former well spouse Linda Welsh puts it. Know about "nights, lifting, and toilet" in a *home* setting. Or listen. Or ask. Be in awe (if not in admiration), and show this appreciation and respect in some way. ("Do you *USUALLY* do all this by yourself." Follow that with "Do you know how to get help if you need to?") Don't join the conspiracy of silence. We're in awe of you; try being in awe of us.

And, when the time is right (which, in my experience, is soon), support us (See this book's chapter, "Is it nursing home time?"); in front of care receivers and at patient-discharge meetings, say things like "It no longer seems feasible that at-home caregiving continue."

(A thought: Perhaps health care workers somehow subconsciously know, or have subtly learned, that these kinds of supportive attitudes and policies, applied consistently over a period of time, might result in the consciousness-raising of the caregiver -- that is, make him recognize his oppression and then choose to cease being a care giver. And perhaps health care workers know, on a conscious or subconscious level, that it would be impractical for society, at this time, if large numbers of caregivers decided to quit. And perhaps that's an

underlying reason why the “collective consciousness” of the health-care system doesn’t acknowledge the reality of caregivers or caregiving. Perhaps that helps explain the conspiracy of silence.)

Recently the American Medical Association took a first step towards recognizing the importance of the health of caregivers and incorporating this recognition in doctors’ treatment of ill spouses and family members. This step takes the form of a new Caregiver Self-Assessment tool available on its website, for physicians to give to caregivers, or for caregivers to ask their care receivers’ physicians to access. This tool is a series of questions for the caregiver to fill out, about her or his own health, the idea being to look out for the caregiver.

However, my own feeling about the wording of these questions is that, while it might help raise consciousness, and while it is a beginning, it is far from an end. Here are some reservations: First, the questions are almost completely not about the *conditions* under which the caregiver works, but about the caregivers’ state of health -- physical, mental, and emotional. And many caregivers might not yet have any of the adverse symptoms mentioned, or might not want to admit to these symptoms (since they could be interpreted as weakness or self-pity or inability to “cope”, and perhaps used in some way against the caregiver). Also, such adverse symptoms (such as a bad back) might develop years later, perhaps well after the caregiving has ceased, when it is too late to do anything about them; thus the emphasis is not placed on *prevention* of caregiver ill health and catastrophe. I would feel a lot more comfortable about that “tool” if it contained more questions about the conditions of caregivers’ lives and work, and only about how the caregiver is reacting to those (undisclosed) conditions.

Second, the tool does indeed offer suggestions, but they are all of the general nature we have already seen ad infinitum, such as “consider taking a break” and “see your social worker about resources in your area”. The usual well spouse experience is that by “a break” is meant a *short* break (“every once in a while”) and the “resources in your neighborhood” are minimal or non-existent, and prohibitively expensive.

Thirdly, none of the tool’s suggestions involved the possibility of discontinuing the caregiving; in fact, the unwritten assumption is that the caregiving will continue.

6) This is a fantasy, although it’s reality in some individual cases: Treat us special. Offer us a lunch or dinner tray. Have more comfortable chairs in the rooms. Ask us to present at one of your colloquiums (about our area of expertise -- namely, well spousery and caregiving). Utilize us, and give us something like professional status.

The following anecdote strongly suggests that not only doctors and nurses

of patients with chronic illnesses, but all doctors and nurses, and physical therapists too, need to be aware of caregiver issues and conditions. A well spouse we'll call Joan reports that, because of her many years of lifting her husband who has multiple sclerosis, she has sustained a shoulder injury and has to go for physical therapy on a regular basis. No one professional has suggested that she and her shoulder be relieved of this lifting. On the contrary; the attitude of her physical therapist has been, "Oh, you HAVE to take care of your HUSBAND. But avoid all OTHER strain on your shoulders." When Joan noticed that other physical therapy patients were getting notes to bring to their bosses that would excuse them from certain strenuous aspects of their job, she half-jokingly asked whether *she* could have such a note to bring home to her "boss". The therapist's response was to laugh, dismissingly.

There is something wrong with a society where it is known that lifting is injurious to someone's health but that someone is nonetheless required or expected to continue lifting. Physical therapists and other health care workers should be on the alert for this kind of thing, and society should strive to be such that these health care workers have options to offer.

Dr. Suzanne Brennan has given some thought as to why professional caregivers are often not quite tuned in to the plight of at-home caregivers. "Many professional caregivers," she explains, "have, in their own lives, been PERSONAL caregivers and perhaps they still are, and perhaps they have kept their own losses -- and loss ITSELF -- at bay. They might say, 'I always knew I wanted to be a nurse,' but might not realize that this is often because they feel COMFORTABLE and IN CONTROL in that role, and not necessarily because they truly WANT to be nurses. To be more empathetic of their clients' and their clients' families, they need to learn to face their own losses in realistic ways. Perhaps medical and nursing schools should have staff members whose specific roles would be to put their students in touch with their own losses; it could be woven into the curriculum."

And here are some suggestions for social workers:

1) Ditto Suggestion #1 directly above, for hospital personell, about watching out for sugar coaters and non-solutions. Of special mention: Don't assume we love our care receivers (or even love "the way they once were"), and don't assume that care giving is, or continues to be, our choice. That includes, don't assume that we want our care receivers to live forever.

Apparently the courses required to be social workers don't always include material on the lives of the future clients. I say this because some social workers seem quite uninformed. Linda Welsh, in "Chronic Illness and the Family", relates how "a naive social worker told a woman who had been caring for her bedridden

husband for twenty-five years that she was filled with anger, rage, and hostility. 'No shit,' the woman replied, with understandable sarcasm. So, before you counsel us, please learn about us, and don't waste our time telling us obvious things that we already know.

2) Try not to talk too much "social-worker-ese." My own pet peeve is "u-huh" (with the intonation and implication of "Yes? And what else is new?") Too often I have had the experience of describing sufferings, especially nights, only to be increasingly aware, the entire time I'm talking, of a token nod, perhaps a look askance, and what I call "the ol' u-huh refrain." It really does feel like a put-down.

Also, as we're describing our sufferings or concerns, don't interrupt us. In particular, don't interrupt us with "I understand." Even if you truly do understand, we might want to talk about it, anyway. We might not want to be freed from the "burden" of explaining our situations; that might be precisely what we want and need. Besides, maybe we were about to say something different from what you thought we'd say. Also, maybe there's something that you *don't* understand.

3) The next few suggestions for social workers have to do with trying to get help of various kinds for at-home care givers. In general, please know, as care-givers know, that true help (that is, with the physical caregiving, especially nights) is rare. Don't sugar-coat this, and don't let your deep and sincere desire to offer help cause you to give false, time- and energy-consuming "leads" -- and too many useless names and phone numbers. Check out the numbers first yourself. We're tired of making ten phone calls and being repeatedly told "I don't do that kind of work any more." This is one more wild goose chase that could be like the straw that broke the camel's back. (That is, it could send a caregiver over the edge.)

4) If the situation requires that you say "you need to take care of yourself so you can be there for HER," be careful to add something like "And also, for YOUR OWN sake."

5) "In fact," suggests Fern, a caregiver and social worker herself, "instead of giving us the dubious phone numbers, make the calls for us.", and actively assist us in finding help. Says Dr. Laura Mascada, Director of Geriatrics at the University of California at Irvine, "often caregivers are so exhausted, just the thought of one more phone call seems overwhelming to them."

6) And please don't fail to respond to our phone messages, nor say you'll call us and then not.

7) Keep in mind that it's not only equipment we need; it's caregiving help.

8) Please don't let your honest desire to offer true help lead you to offer what is *not* true help, such as unhelpful advice (which sometimes amounts to assumptions and to insult). "Take a day off for yourself" (as though we hadn't thought of that ourselves, and as though that were possible). "Don't be afraid to cry" (as though we hadn't already cried a thousand times). "Get organized; make a list" (maybe we already have made a list. And maybe that's as good -- and as organized -- as it gets.)

9) Maybe we need your shoulder to cry on, but maybe we don't. Maybe we already have shoulders to cry on -- for example, other well spouses'.

10) Leave us our dignity; leave us ourselves. Ask us about our kids, our grandkids, our work. (Maybe we're social-workers, too, or have some related profession that makes us as expert as you.) Call us Dr. or Prof. if that applies, or our first names if we seem to prefer that. Many health care workers have actually asked, "What do you like to be called?" and clients often appreciate that. But, over time, try not to forget our answers!

And again, don't look down at us; in fact, look UP at us!

11) Encourage clients to read helpful, informative, supportive, and consciousness-raising (maybe hair-raising!) books, such as Maggie Strong's MAINSTAY, Linda Welch's CHRONIC ILLNESS AND THE FAMILY, and my own DIRTY DETAILS and STILL THE END. Also, refer clients to the Well Spouse Association Newsletter (called Mainstay, after Maggie Strong's book), and the well spouse website (easy to memorize): www.wellspouse.org

12) Give clients, not only the names of, but information about caregiver support groups and organizations. (These are different from specific disease support groups; those groups tend to support the care receiver more than the caregiver.)

13) Encourage clients to ask for help (meaning caregiving help) from family and friends, and in general encourage self-advocacy (with the mindset, "not selfish, but self-ish"). In this society, self-advocacy is often almost a taboo; yet it is often absolutely necessary.

14) For example, suggest to clients the idea of holding scheduled family meetings, where the well spouse actually asks for help in an organized and professional manner (perhaps actually having a professional at the meeting -- maybe you. You can charge your usual hourly fee for a home visit.) Some helpful things which a well spouse can ask for (with the mindset, "contribution, not handout") are: care giving help on a regular scheduled basis with the well spouse out of the house, permission to call in the event of emergencies, going over forms

(hospital forms, insurance forms, agency forms, etc.), helping to find home health aides or back-ups, making phone calls to doctors, agencies, insurance companies, etc. Or, as Linda Welsh suggests in "Chronic Illness in the Family", "pick one person... Give this person a list of friends, relatives, and medical people who should be kept informed about your spouse's condition. When your spouse has come through a crisis, ask that person to call those on the list with the medical update." if not "ready" to do some actual caregiving, relatives and perhaps friends can just-plain visit the care receiver -- again, on a regular scheduled basis -- or they can do housework or baby-sitting. And (sigh...) relatives and friends can do nice things for the caregiver -- dinner out, candy -- and not expect the caregiver to be a host or hostess during family get-togethers (with the mindset that this situation is, at the very least, comparable to the birth of a baby -- without the joy).

It might be helpful if social workers could talk with the client about the following: Asking for help might not result in actually getting help, but it will possibly provide a kind of closure, both emotional and practical. For example, the info gleaned could figure towards making the nursing home decision, in that the client might learn that, sans nursing home, family members will ultimately not contribute much towards care giving.

15) In general, difficult confrontations could, and I believe usually should, be accomplished in a therapeutic setting. Not only whether it's nursing-home time, but also when, in the nursing home, it's cutting down on visiting time, or separation or divorce time. Handling a chronically ill family member who might have dementia is too difficult and too risky for anyone to handle all by herself without back-up and without documentation. (I asked my own therapist to do this for me in most of the above, and it worked very well; in particular, it made me much less nervous than I would have been about the confrontation.)

16) Or clients could write asking-for-help letters to long-lost relatives. In general, encourage clients not to be in the closet about their "dire straits." (How can anybody offer to help if no one knows that help is needed?)

17) This brings us to the next few suggestions having to do with helping clients make the nursing home decision and in general "rescuing" clients from caregiving when this is indicated. Again, the bottom line is that such rescue be "on the program" and that social workers, along with other health care workers, support the caregiver by insisting that "at-home caregiving is no longer feasible." (See Dr. Brennan's suggestions in the nursing home chapter.) First, a repeat of suggestion #11 about encouraging clients to read helpful and appropriate literature and books. Second: Another perhaps very subtle sugar-coater is the oft-repeated claim that the nursing home decision is "very difficult." Yes, there can be a lot of anxiety and anguish involved, but this is often due, not so much to the

nursing home placement, as to the illness itself. Also, it's often *implementing* the decision that's difficult. This "difficult decision" mindset can have several detrimental repercussions.

Like the mindset of equating care receiver with "loved one," it can produce guilt feelings in caregivers for whom the nursing home decision is *not* difficult -- who might actually feel quite sure and comfortable, maybe relieved, even joyous, with that decision. In fact, in some perhaps vague way, the nursing home decision being "difficult" is sometimes one and the same as the care receiver being a "loved one." That is, the nursing home decision being "difficult" is often supposed to be *because* the care receiver is "loved" (and therefore the caregiver cannot bear to "put her in a nursing home"). In other words, the caregiver for whom the nursing home decision is not "difficult" might feel guilty because she thinks this might mean that her care recipient isn't a "loved one."

Perhaps along these same lines, the societal myth that making the nursing home decision is or ought to be "difficult" can, like all myths, propagate throughout society into reality. So caregivers actually do find the decision difficult, or more difficult than it otherwise would be. As one well spouse put it, "if everyone says it's difficult, I guess it must be difficult." As another well spouse said, "if I'm not finding it difficult, there must be something wrong with me."

So the myth that nursing home placement is "very difficult" can delay nursing home placement even in cases where the decision is not difficult.

18) As mentioned in the "nursing home chapter", caregivers and family members often imagine nursing home qualms, whereas the qualms are actually about the illness (and possible death) itself. It might be helpful to tell clients (both caregivers and care receivers), in whatever words seem appropriate to the personalities and situations involved, that avoidance of nursing home can never imply the avoidance of the reality and progression of the illness. That is, nursing home avoidance cannot be an effective denial device.

19) Here are some ideas as to what caregivers and social workers can say to frightened and/or stubborn care receivers who beg, "Please don't put me in a nursing home," or who have in the past extracted a no-nursing home pact or promise.

What works for some care receivers has been "You're not safe without being in a skilled care facility, and all I can provide is an UN-skilled care facility" or "You're ALREADY in a nursing home -- and a vastly understaffed and under-equipped one, at that."

Care receivers who are trying desperately (and un-wisely and selfishly) to deny just how far the illness has progressed can possibly be handled by being

gently told, in different words of course, “Just because you’re not in a nursing home doesn’t mean you’re not nursing home material!” And maybe the next time they beg, “Please don’t put me in a nursing home,” try asking them, only slightly sarcastically, “Oh, now, why would anybody want to put you in a nursing home?” or even “Why do you say that?” (Why, indeed? Answer: Because she knows darn well, or senses, that it might in fact be nursing home time.)

20) If a caregiver seems to believe that care receivers will live longer or better in their own homes than in nursing homes, inform her of some instances and statistics which indicate otherwise.

21) If an entire family says no to the nursing home idea, take the caregiver aside and listen to what *she* has to say. Ask appropriate questions if you need to, such as what her actual caregiving duties are, how much sleep she’s been getting, how her health has been, what restaurants or movies she’s been to (or hasn’t been to) lately, how her kids are doing. Give her a perspective, and a taste of normal life. Gauge her answers and her reactions, don’t be invasive right away, but maybe eventually ask, “Do you really want to be doing all this?”

22) If caregivers and/or families say they don’t want you to interfere, then interfere in non-invasive ways, like handing them literature or introducing them to other families who have already made the nursing home decision. Keep in mind that what people ask for and what they want are often two different things. If possible, interfere a little, despite what they ask, and see how they react. If they insist they truly do love the care receiver so much that they couldn’t bear the idea of “strangers” taking care of him, or they’d miss not having him around the house -- or if they say the caregiving’s really “not that bad” -- or they want to (or “might as well”) see it through to the end, just let them talk; probe a little more deeply, maybe be a little more aggressive, and stare into their eyes knowingly and compassionately or, again, introduce them to family members of nursing home residents.

23) When helping caregivers and care receivers make, or not make, the nursing home decision -- and in general, when making plans or just conversing -- consider, when appropriate, the possibility of *subtle* dementia, which is usually not officially diagnosed. Many diseases, such as multiple sclerosis, which were previously believed not to affect the mind, have been recently studied and in some cases proven otherwise. Moreover, sometimes the mental symptoms of a disease manifest ‘way before any other symptoms. And there is some evidence that, over a long period of time, paralysis, or even reduced activity, can itself (rather than the disease) rob the brain of certain functions. The verdict is far from in on all of this, but surely something is going on.

The key seems to be that phrase, “certain functions.” That might be why some dementia has been so hard to detect, and so hard for society and for

individuals to accept. Things can be compartmentalized. Thus, for example, Nora's husband with his PhD in chemistry could visit and discuss physics with my husband Jeff (with his PhD in physics), even though there have been serious ways in which neither of them can connect with other human beings, and both have greatly hurt and harmed their families.

None of this is any secret to most workers in skilled care facilities. "Pretty much everyone here has some degree of dementia," I've been told; often the person adds, "of course, it wouldn't show up on any test." Ignorance or denial of subtle dementia, when it exists, can result in extreme frustration for family members, as well as in grossly un-informed and unwise decisions, in particular decision about the care plan as well as financial decisions on the part of the person with dementia.

Don't expect family members, for example, to do the impossible, such as reason with a demented care receiver; think twice before recommending "better marital communication." And don't forget that even subtle dementia can cause a care receiver to be abusive, both verbally and physically. (And from personal experience, I want to add the following: Psychiatrists, sharpen your tests for incompetency. I have literally begged for help, and then looked on helplessly as my husband hoarded his entire disability and social security checks, away from my minor son and me. I had to hire a lawyer to get support. Often, it seems, everybody wants to protect the patient and nobody wants to protect the patient's family.)

To avert the damage done by *slowly progressive* dementia, social workers (and elder care lawyers) could alert the couple *before* dementia sets in, or before already existing dementia gets dangerous. This could be a touchy situation, but for some families it could make a difference. I wish that, many decades ago when my first husband was initially diagnosed, a professional (our elder care lawyer or a health care professional) had said to us (in particular, to him), in well-chosen words perhaps more tactful than the following: "Listen hard. I know it hurts to hear this, but it's common for people with long chronic diseases to eventually experience some dementia. I know you don't want to hurt your family, and there are legal ways to insure this, and to protect your spouse and children..." I believe Jeff would have listened. Our children and I would have still gone through the hurt coming from Jeff's dementia, but we wouldn't have gone through the HARM.

24) Concerning making the nursing home or any other decision, a well spouse named Lu cautions, "Just because things are going well, doesn't mean that everything is all right." I think she meant all right with the caregiver.

25) If you yourself have, or once had, a situation in which you were a caregiver, make sure that you're in touch with any of your own caregiving issues,

and don't let them affect how you treat your caregiver clients. For example, don't project your own guilt, or expect clients to feel and act the way you did or do.

26) Last but not least (even though a repetition): In all situations involving chronic illness, cultivate the mindset that caregivers should have the privilege of deciding *not* to continue to be caregivers. Even if society is not set up to make this easy, at least YOU can have the right mindset, and be a friend to caregivers. Recall Dr. Brennan's statement about "fairness in a relationship, even in the face of illness". Forced marriage, as well as forced relationship, is against the law.

What follows are suggestions to policy makers. These include people in administrative positions -- in hospitals, nursing homes, home health agencies, insurance companies and even, sometimes, agencies and organizations that are not apparently health care related:

1) Everyone seems to concede that family members of hospital patients and nursing home residents are "valuable members of the treatment team." But in actuality, how "valued" are these "valuable members"? Are they valued enough to be treated well? Notwithstanding the fact that they aren't paid (In fact, they're the ones who pay) and though there might be practical reasons why they can't be paid, the feelings and impressions of some family members about this state of affairs are not insignificant .

Re-read the chapter on what being a nursing home family entails. As to the part about how we sometimes feel "even lower on the totem pole than volunteers," reflect that perhaps it wouldn't be a bad working model, to try to think of family members and visitors as volunteers. Offer us free meals. And if the budget doesn't permit that, perhaps try to *arrange* for the budget to permit it. Stock the fridges in your halls with juices and cookies. Have a "Family Member Recognition Day," not only to honor family members and caregivers, but also to raise consciousness and help change conditions.

Yes, we would "visit anyway," no matter how we were treated, because we want or have to. Perhaps society is set up to take advantage of this state of affairs, but that doesn't make it right.

2) When my M.S. husband lived at home, I phoned countless churches and organizations such as Volunteers of America and asked for help with "nights, lifting, and toilet." "Oh," I was told, "we don't have THOSE kinds of volunteers." My suggestion: Have "those kinds of volunteers."

There are many possible sources of "those kinds of volunteers": nursing students, students in general, especially (for nights), students who study at night. We ourselves eventually found a few such volunteers, mostly by word of mouth,

and mostly people who for various reasons needed to be useful (even if only for short periods of time...). in other words, just-plain volunteers. In fact, what IS this business of “those kinds of volunteers?” To some extent at least, a volunteer is a volunteer; if she’s willing to wipe brows, she might be willing to wipe bottoms.

If we, a mere individual family in dire straits, managed to find “those kinds of volunteers,” imagine what a coordinated effort, backed up by whatever backs up your other services, could do.

3) To whoever makes out home health aid agency forms (or any forms at all): Please be accurate on those forms. I lost count of how many times we checked, under “Services Needed,” “transferring,” only to be sent people who thought “transferring” meant *help* in transferring. There’s a huge difference. The people they sent hadn’t a clue about “lifting,” -- that is, about lifting someone dead-weight. When these people arrived at our doorstep, unable to transfer, I had to do it myself, just as though they weren’t around at all. It was enraging and horrible, and it happened again and again, more often than not. It can break the spirit.

Likewise, “toileting” does not mean changing catheters.

4) More about agency forms: They got in our way big-time. We lost a great many potential home health aides because they didn’t want to or couldn’t sign those forms. (The work was only part-time, or they were merely replacing our regular attendant for one day; the small amount of work wasn’t worth jeopardizing any welfare or other public assistance they might be receiving. This happened again and again, perhaps more often than not.)

YOU’RE the experts. There must be some way to avoid, or minimize, detrimental question on those forms.

5) Another idea for agencies who fund families in chronic illness situations: Just GIVE us the money. So what if -- worst-case scenario -- we spend it on a new hat?! That, too, would ease our burden. And if we could live our lives knowing that a “no-show” means a new hat, or “Thai take-out” or any special treat of our choice (maybe extra home health aide hours at a later date, or a house-keeper or babysitter, both far easier to find than home health aides, and much more likely to show up), that, too, would ease our burden.

“Absolutely!” says Dr. Brennan. “The way funding is handled now, adult recipients of funding are often treated like children. Once recipients have been evaluated and given funding, there should be trust rather than distrust.”

This would be equivalent to paying us for caregiving -- on “no show” days

or even on a regular basis. That is, hire us as home health aides. End the “no family member” taboo. End also the myth that extensive training, rather than innate strength, intelligence, compassion, and experience, is necessary for this job. This idea will be further explored when we give suggestions for legislators.

6) it is pretty well known by at-home caregivers and by agencies that home health aides who show up, and who keep showing up, are extremely hard to come by. (Most well spouses I have spoken with estimate having had, over the years, about 40, of which one or two have continued to work out.) Along these lines, here are some vital suggestions:

A) Don't send us *lists* of phone numbers of home health aides, along with a disclaimer that you're not vouching for their competence and that we need to check them out. “Checking them out” often involves (besides time-consuming calls for us) allowing them in our homes, and some of them have been unsavory. (Remember that, in many such homes, there are young children around.)

B) If you do send us such a list, make that an *updated* list. Of four lists of four people each sent to us by a well-known local agency, none of the sixteen worked out. Moreover, at least half cut our losses by telling us, right off, “Oh, I don't do that kind of work any more. I haven't done that for about three years.” Again, your lists should be updated.

Caregivers are often *already* discouraged and bitter. We don't need to hear that again and again. We know you want to help, but please, quantity is not what we're looking for; often it's the very opposite of what we're looking for. All we need is *one* person who will show up and work out. Any conspiracy of silence around this is not at all helpful.

C) Try to have back-ups. Antonia, the New York well spouse whose husband died in their home, was continually being told, “I'm sorry the aide didn't show, and we don't have a back-up, either.” We understand the difficulties involved -- for example, back-ups have to be paid to be back-ups (Why, I wonder, don't school substitute teachers?) -- but I still believe that, rather than these difficulties, it is society's attitudes and ignorance that are responsible for the conditions under which families beset by chronic illness live. Again, society could make greater efforts in the back-ups category.

D) Please, please, PLEEZE don't claim that this sort of thing “almost never happens.” That can make us crazy. It can make us scream, “It CAN'T keep happening ONLY TO ME.” Besides, it's dishonest, and it's talking down to us.

E) Think twice before sending “experts” to “teach” us how to use various equipment; make sure we truly need to be taught, that we're not experts

ourselves (through experience, and perhaps unwilling). When you do need to send us ‘teachers,’ make sure these teachers understand what caregivers’ lives are like and train them to:

- I) not hold unrealistic expectations of us
- II) not talk down to us (in particular, not use sugar coater language)
- III) treat us with dignity
- IV) inform us of any options that might exist that free us from doing what they’re teaching us

8) It has been the experience of many many caregivers that, unless their care receiver is an inpatient in a hospital or Rehab facility, the family is pretty much forgotten by the health care system. Moreover, there is a conspiracy of silence about this. If, for example, we want to speak with a hospital social worker about, say, nursing home options, we are promised phone calls back and then don’t receive them. This happens again and again. And in the same facility, the moment our care receiver is an inpatient, we get called without first calling. This too happens again and again. Only “under the table” do random health care workers inform us of this state of affairs.

The suggestion: First choice: Change that state of affairs. Caregivers ALWAYS need your services, not only when the patient is an inpatient; in fact, they need them more when their care receivers are not inpatients. Second choice: Stop the conspiracy of silence and be honest.

9) Nursing assistants, although paid and in a chosen profession, are still caregivers and might feel stressed out and unappreciated, often to the point that they quit (or are let go because they “went off the deep end.”) Also, as Dr. Brennan was quoted in an earlier chapter, their professional issues might connect up with some of their personal issues (especially, again, if they were or still are caregivers themselves). In an article for “Update on Aging,” Spring ‘95, Mary Ann Wilner, Ph.D., makes a good case for “support groups for nursing assistants.” Besides a place to air and acknowledge stress, such a group could also offer education, affirmation, and collegiality. With funding from the National Center for Nursing Research of NIH, Dr. Wilner’s group began a pilot project of support groups in sixteen different nursing homes. Some of the results: reduced feelings of stress, enhanced self-confidence, reductions in turnover and, finally, “fewer problems among residents who were attended by regular group members.” I might add a conjectured positive result: an easier life for the family members of residents.

10) Included in the suggestions for social workers were mention and elaboration of dementia, especially subtle undiagnosed dementia. You, also, need to be on the alert for it (perhaps simply by asking the care iver), and to be very cautious about allowing such patients to be in positions where they control

large amounts of money. Nora's husband squandered \$9,000 in two weeks; Jeff got in a mood one day and made phone calls setting up an account in his name and then having his monthly disability checks, on which his family was living at the time, be deposited into that account. And Amanda's husband suddenly turned gambler and blew their entire savings of a million dollars.

11) The next few ideas concern Hospice. "Hospice was the best thing that ever happened to me," says Dr. Brennan, about her own experience with her dying father. She also assesses, "We have much to learn from Hospice. Hospice is a good model." Nonetheless, there are three C's which, so far, hospice needs to be more aware of than it already is:

A) chronic illness, which lasts for more than six months, and which can be just as "acute" as an illness which is literally in its last six months. So the "six month rule" needs to be changed. (At present it is often "stretched", which is of course extremely helpful for the family but also a source of worry. When Fern's family, after several years with her ill spouse still not dying, was at last taken off Hospice, it was very upsetting indeed, and before that the worries and fears had been looming for years.)

B) the caregiver. When evaluating whether or not Hospice is the way to go for a particular family, interview the caregiver extensively. Find out what *his* needs would be.

C) custodial care, not only medical care. And enough of it.

12) More on hospice: Don't proceed on the assumption that home is necessarily the best environment to die in. Not every home is a good home and not every family is even functional or non-abusive, let alone happy and loving. Keeping up appearances is what many families are about. Before making hospice-related recommendations, find out what the dynamics truly are.

Remember, too, that when a patient says, "I want to be home," what she really might mean is "I want to be WELL." When hospice begins and she discovers that it doesn't make her well, she might want to re-evaluate her decision.

As Dr. Laura Mascada, Director of Geriatrics at the University of California at Irvine, says, "You can feel isolated even if you're surrounded by family." Again, keep abreast of what's really going on.

Society tends to romanticize "the good old days," when "the extended family" did the caregiving. I wonder how that actually worked out -- especially in cases of chronic illness. Indeed, there are situations where even ten caregivers in

a home setting isn't enough. Also, not all "extended families" were that "extensive"; some were small. When you consider the prevalence of the work ethic, and gender and other biases, one might wonder whether "the good old days" actually were as good as we might believe.

And now we come to our last batch of suggestions -- for those *really* in charge, meaning in charge of those in charge, namely our legislators. Yes, the system is big, too big for its britches, and it's difficult to know who, if anybody, is "really in charge." Here, nonetheless, are ideas which I hope will help change attitudes at least:

1) Many people feel that the Medicaid laws are "about as fair as they could possibly be" because they base things on people's needs. Even very politically liberal or radical people sometimes say, "it's like socialism" and "Medicaid really does get it right."

Yes, there are some aspects of Medicaid which are both "fair" and "like socialism." And the Spousal Impoverishment Act is certainly an improvement over what we had before. But let's examine things a little closer. The socialistic -- and, supposedly, capitalistic -- ideal is "To each according to his [her] needs; from each according to her capabilities." But when calculating how much from and to "each", let's figure in the equations a little well spouse and caregiver awareness (complete with "nights, lifting, and toilet").

Starting with the capabilities, here are some thoughts: By the time we're applying for Medicaid, our capabilities are very probably not all that great because we've already depleted so much of our finances on illness-related expenses, including loss of career and/or career opportunities. We're also emotionally depleted, not as emotionally able to live under "Medicaid conditions." We've already had more than our share of signing forms, dealing with authorities, feeling sad, scared, powerless, frustrated, worried, angry, and in general not like normal citizens and human beings. Perhaps we feel like saying, "We gave at the office." So under Medicaid as it stands, we are asked to give more than our capabilities.

Now for the needs: Financially, we know that we will, or might, continue to have unpredictable miscellaneous disease-related expenses, things we might not think to put on the Medicaid forms. That is, our financial needs are great. Emotionally, we need to be badgered and bothered *less*, not more. I've heard that Medicaid officials and social workers are increasingly sensitive and thoughtful, but there's no guarantee of that in any specific case; also, the laws themselves put caps on how considerate individuals -- even individuals "in charge" -- can be.

Getting back to the “socialism” theme, Karl Marx said that, if it isn’t everywhere, it can’t be true socialism. People about to go on Medicaid feel like second- or third-class citizens when only WE have to be “socialistic” -- that is, only WE have to give “according to our capabilities” -- when everyone else is allowed to be “capitalistic” -- that is, keep the money s/he makes or has saved, independent of how “capable” s/ he is. As we know, “separate but equal” doesn’t work, partly because things can never be separate; things interact, and know about one another.

In fact, under true socialism, it’s the community that’s responsible for an ill or disabled person, no less so than the well family members. In other words, it’s not OUR fault they’re sick, and it’s no more our responsibility than anyone else’s.

What DO well spouses want? (To paraphrase Freud, “what do women want?”) Well, as mentioned earlier, “we already gave at the office.” And many of us feel that we would like to not have to give more and again. We would like society to give the rest. An anonymous well spouse plaintively and astutely observes, “If it takes a village to raise a child, then it also takes a village to care for a chronically progressively ill adult. Look at all the programs we have for kids [which I applaud]; where’s the village for us?”

We would like to have to do NO more care giving -- not “advocacy,” not “helping out”, not filling out forms, and not feeling that we HAVE to visit ONLY because we need to check on the care our ill relatives are getting. We would like whatever caregiving we do to be because we CHOOSE to -- and choose freely and informed-ly.

Medicaid-wise, we would like, not only for the finances to be taken care of, but to be taken care of in a way that WE DON’T HAVE TO WORRY. Forms feel worrisome, home visits and too many phone calls feel worrisome, and the stuff we hear on the news feels worrisome. We would like to not have to worry; we would like to feel secure. All those variables make us nervous. Being suddenly socialist also makes us nervous. We don’t mind feeling appreciative and grateful (as YOU should feel appreciative and grateful to US, for all WE’VE done), but not in a fearful sort of way.

Who or what decides what constitutes “impoverishment”? Who or what decides what constitutes “assets”? Why do so many people about whom these decisions are made not quite trust those in charge of making the decisions? Why are we so afraid of becoming impoverished? Why should our “assets” be taken away, just because we’re the ones who “have” the sick and/or disabled people? And what ABOUT that word “have”? What does it really mean? In other words, really MANY changes need to be made in society (both in legislation and mindsets), not only those concerning chronic illness.

3) Here's an idea that would take time but might do the trick: A nursing home tax, for everybody. Well, we have a school tax. Just as our "young" is everybody's responsibility, so are our "old", as well as our sick and disabled not-so-old.

4) Recently there's been talk of tax breaks for at-home caregivers. What, in fact, about a "break" from paying taxes altogether. Moreover, Dr. Brennan suggests a tax break for those who VOLUNTEER, whether at-home or in skilled care facilities? After all, these caregivers are saving the state a lot of money, far more than the amount of any tax.

Here are the bottom-line suggestions to *all* health care workers "in charge:" Caregivers are workers, and thus should be given the same rights that, ideally, all workers have:

- A) the right to be paid
- B) the right to be paid FAIRLY, in particular ENOUGH
- C) the right to be paid overtime (with "regular time" being eight hours a day)
- D) the right to benefits, and perks
- E) the right to weekends and paid vacations

When this is brought up at well spouse meetings or conventions, some well spouses laugh. It's the laugh of the downtrodden, the laugh of the unlucky, the laughter of people who are used to getting the short end of the stick.

And here's another caregiver right: the right to quit. (And to receive a good severance package)

Maybe get a promotion.

Maybe go on strike.