

AUGUST 28, 1998

MELYNN GLUSMAN: This is an interview with Florence Soltys, is it Soltys?

FLORENCE SOLTYS: Um hmm.

MG: The interviewer is Melynn Glusman. We are at Mrs. Soltys' home in Chapel Hill, North Carolina. This is part of the interview series, Listening for a Change, part of the Southern Oral History Program's interview collection. The date is August the 28<sup>th</sup>, 1998. The tape number is 82898-FS.

MG: Okay. Why don't we start with just a review of some of the things that we've been talking about in terms of your life history and what brought you to the work that you do with death and dying.

FS: Well, that's a really good question and I'm not really certain. I think there are a number of things that probably have. When I grew up in a rural area in Tennessee, I was the oldest grandchild much loved by my grandmother. I was the only grandchild to have red hair. None of her children did. So I was always her favorite, and used to spend a lot of time with her. In those days, children and people who were ill were sort of focuses of women's lives. So I remember going to visit people when they were sick, particularly older people with her, and gardening with her and how much fun that was and how special I was always treated by these people because I was Mrs. Gray's granddaughter. So I expect you could say that was the beginning. My parents were always very community oriented people, who were very involved in civic things and also neighbors who might need a helping hand or something. We were always taught that as we grew up; that was your responsibility. Then I went away to Boston to school. Of course going into nutrition, one is in somewhat of a helping profession there, in a hospital setting. I was a young green kid who had the great fortune of working with Jocelyn [sic], the great diabetes person, and Paul Dudley White, the cardiologist. Not recognizing how fortunate I was as I was a student and later working there. Now I'm reading about these great men still today forty years later and how wonderful that it is that I had that experience. So I've been lucky. After some time there, some years there, I met my husband, who was a medical student. We were married when he graduated. Then in the early sixties, there was a great deal of turmoil in the Boston public schools, and they were needing people who would go into the black schools to teach. So for three years, I taught in what was basically a black school in Roxbury called Girl's High School in which many troubled youngsters were. I had a great time with that and really loved them. Sort of using my background in nutrition. I didn't have the education background, but I loved teaching. I think probably that was my beginning of really being interested in teaching. Until very recently I still heard from

a lot those students from the early sixties that I worked with there. My husband worked at the reform school. In those days, they had reform schools in Massachusetts. He would see many of them in the reform school that I was teaching when they got in trouble and disappeared from school. So we had a link and a connection there with what was happening. Then I think as I told you, I became pregnant with our first child, Jacqueline, who is a linguist, a Russian linguist and has just produced our first grandchild, Sophia. She and her husband are at Cornell. So I stayed home for many years after that. In Boston, I was involved in a lot of civic activities there, community organizations, organizing. I've always enjoyed organizing things and detailing. So I did a lot of that. We lived in a neighborhood that had a lot of older people, which always fascinated me. Their stories, their sense of history, the wisdom that they had accumulated just always has excited me. Then in '75, we moved here because John came to the medical school. I still didn't work for a number of years here. I did a lot of organizational things. There was not a Meals on Wheels program here when I came, which I couldn't understand because in Boston it was very active. So in 1976, I organized Meals on Wheels, with the help of a lot of other people, I'm not saying I did this single handedly, which now exists still today. A couple years ago, I missed the twentieth anniversary, they had a big celebration. I happened to be unable to go but it was very exciting to think that the organization was twenty years old. Then in the late seventies, there began to be a lot of interest in developing this new program called Hospice. The Connecticut Hospice had been built and there just started to be more and more interest. So there was a committee here, and I was a member of that committee that began to look at and start Hospice. It started out that Wake, Durham, and Orange were together as one Hospice. Geographically it was enormous—it included some of the rural counties-- and didn't function. But eventually Wake broke off into another Hospice, and Orange and Durham remained as they do today with Granville. That's an area where I've always had a lot of interest because I can remember when I worked at the Mass General, of times seeing people, older people, who would beg me to go read their charts and tell them did they have cancer: 'Am I dying? There are things that I want to do.' I was a young kid in my twenties, mortified that no one would tell these people what was wrong with them. I knew if I did, I would be fired. I was often scared to do it because my husband was earning twenty-five dollars a month as an intern, and we had to eat. But it's something that stayed with me of people's right to know and right to control their own lives and make decisions. Health care has changed tremendously since then, not

that it doesn't have a long way to go. But I think that was, that probably planted the seeds for my interest in Hospice, and people being able to maintain and know what's going on and make decisions about how much care they wanted. Of course, there was not technology then either. So that wasn't something that played a part as much as it does today. But in the late seventies, there was not really that much technology either. I remember the first kidney machine in Boston when I was a young student there. The first kidney machine was done at the Peter Bent Brigham, which was across town from the Mass General. We had a committee that decided of all these people waiting for dialysis that they thought had final kidney disease, who would get the machine, because only one person could have it at the time. So that was sort of, as far as I could see, the beginning of the revolution of technology and people being able to live longer--many diseases that gave you a terminal diagnosis. You'd see these young people with kidney disease, and you knew they couldn't live because there was no way to do anything about them. It was usually a very uncomfortable kind of death. I guess another thing I remember was from Mass General was John Rock, who was an older man that I spent a lot of time talking with toward the end of his life. He had discovered the birth control pill. I can remember if I didn't go by to see him--he was in the hospital-- he'd call me in my office to come talk to him. He liked to tell stories about his life, and I liked to listen. And so often, I think, he would say to me, 'When you're in your fifties and sixties, Florence, think of me, and remember that I've done more to change society than anyone you'll be able to name at that time.'

MG: When you say he discovered the birth control pill--

FS: He discovered what it would do. That it would maintain the ability of the woman not to be fertile, and it wouldn't harm her.

MG: And he developed, he actually developed the pill.

FS: Yes, yes, yes. Right. He said, he was widowed, he said, 'What I've done is freed women to make choices.' He was almost like a woman's libber. There he was an older man who understood the issues. He was fifty, sixty years ahead of his time. At that time, he was in his probably mid to late seventies and at the end of his life. But he loved to do life review and tell you about his growing up. I think I've always been fascinated by knowing when I meet people and see where they are today what brought them where they are. It's absolutely wonderful. Whether it's a person who's picked cotton for fifty years on a farm in rural North Carolina or whether the person's been a famous professor or whatever. It's

just interesting to know who they are and where they're coming from. To me it's so much of the health care in geriatrics, particularly where I work, that you need to know that and respect it. Otherwise, you're just treating little parts of that person. The whole person and their functional level and quality of life supercede usually the disease process, almost, because often it's a chronic disease anyway that you're not going to reverse. Pain control is very necessary with people, if they have it, toward the end of their lives too. But I really find that very necessary.

MG: So what specifically do you do with folks who are at the end of their lives to help them figure out where they've been?

FS: As a social worker often it's spent dealing with the family and with the person. Logistically probably those kinds of things that they may need: services in the community, linking them, seeing connections, if they're eligible for Medicaid and other kinds of assistance like that, to help them navigate the system, which is very fragmented and often difficult. People may not know how. But the other thing is to listen to them and to hear them and to know what they want. To help families listen to each other and if you can, help facilitate 'I'm sorry', 'I love you', 'I wish I had done this', or 'Didn't we have a great time here?', 'Wasn't that a wonderful party we had,' birthday experience or whatever. So that those memories are there for the people who leave and helps the saying goodbye to be easier as well. I'm thinking of one woman that I saw in our clinic here in Chapel Hill, probably four or five years ago. We have a geriatric clinic here that's interdisciplinary, on Mondays. All of us are faculty: the geriatricians, the nurse practitioner, myself, the physical therapist, and the occupational therapist. We have nutrition and geropsychiatry available to us. The patients that we see are specifically people that need a team, that are very frail and have a lot of issues to be dealt with whether they're psycho, socio, physical, mental, whatever. I remember this particular woman. I think she'll never leave me, as so many people haven't, they're so much a part of me now. She was brought to us because she had moved to Chapel Hill with her son from a rural area of North Carolina. They had brought her because she had been diagnosed as having Alzheimer's.

MG: Who was 'they?' Her son had brought her?

FS: Her son had brought her to live with him because she had been diagnosed by a psychiatrist in a Mental Health Center saying she had Alzheimer's. So they thought she couldn't live in this little town anymore by herself. I often am the first person to see patients. We go, and what I attempt to do is get them

to relax and begin to ask them questions about why they're there, who are they, those kinds of things. I'm not a person that ever goes in with a standard kind of set of questions. I hate that. I would rather relate to the person. She sat and wouldn't make eye contact and looked at the floor, spoke in a low voice, and kept answering me that I don't know. Then after a few minutes, we began to talk about where she had lived and the farm and her children and that sort of thing. She began to make eye contact with me and began to talk more openly and quite clearly didn't have Alzheimer's. As we talked, she quoted me a beautiful little poem about a cloud. So I said to her, 'Betty' or I said, 'Mrs. C where did you get that? How did you know that poem?' She said to me, 'Well I wrote it.' I said, 'That's absolutely wonderful.' She quickly said to me, 'I have 200 more at home that I've written over the years.' By this point, she's getting enthusiastic and she also said to me, 'You know, I've got a lot of sculpture too.' I said, 'Oh.' She said, 'Yeah. I've had these visions out of the Bible.' And she said, 'When I have a vision out of the Bible,' she said, 'I get me some clay and I make figures.' I said, 'Oh, well tell me about them.' She said, 'Well, the pack house--this is the tobacco building--on the farm is full them.' She said, 'Somebody told me the roof blew off and they've been there for years. I don't know if they're any good or not anymore, but there's one thing I'd like to know: if they're worth anything before I die.' She told me about how at nine her mother had died and she'd quit school and had raised her four younger siblings and then had married at sixteen and had raised five children and had worked on this farm. A lot of the sculpture she had--she couldn't afford clay--so they were made out of red clay that she could dig on the farm. The ones that were painted were done with paint that was left over from the house or whatever. So I said to her, 'Would you like me to find out about your art?'—and of course I'm absolutely dying, because I love folk art. I immediately called--oh shoot, I'm blocking his name now--the person who's the big folk artist over in Raleigh. He was so excited that he drove to the little town, called her son, drove to the little town the next day and came back with a huge station wagon full of this art, which was absolutely glorious.

MG: Oh my gosh!

FS: We were all so excited. Of course, we bought her a big thing, a bag of clay, and because she hadn't sculpted in quite a while and got her on anti-depressants so she'd feel better. She--then he said to me--Roger Manley--I was trying to remember his name. Sorry. So Roger called me and he said, 'I'm going to Europe for a month.' But he said, 'Don't you let her sell those things to a dealer.' He said, 'If she wants



to sell them, when I come back, I'll help her and get the maximum price out of them because they'll sell on the New York market because folk art is big. But he said, 'But if she doesn't and wants to give them to a museum, I'll help her do that.' So I talked to her about it and talked to her family. When Roger came back probably five weeks later, she said, 'I've made a decision.' She said, 'I've decided to give that artwork to museums because I want my great-great grandchildren to know who I was.' So her things are in two museums today.

MG: Which museums?

FS: In the North Carolina Wesleyan and the North Carolina State, which both have folk art collections. So that's an example--.

MG: What a thrill!

FS: That's an example of an older person who was dying and what she--we talked. I spent hours with her, talking about her life and resolving some issues that had gone way back and some feelings of deprivation from her background, et cetera. She loved to play the guitar and sing. So I would go over and she would play the guitar and sing to me, which was wonderful. Very old songs. She had wanted to play professionally in a band, but women couldn't when she was growing up. When she was dying, I had visited with her a few hours before she died. She was still conscious and we were able to, I was able to just hold her hand. I was able to talk to her about some of the things that we had talked about. Her son called me after she died and said it was very peaceable. The family was there, and she went very easily and was able to say what she wanted about her funeral and everything. So she was given enough time. It wasn't a sudden situation. It was a life that if you'd looked at it, here's not a woman who accomplished great things but she'd raised five children, poor education-- she and her husband both. All the children were college grads, some with graduate degrees, who were all professionals and making a contribution to society. And she was able to leave feeling that she was leaving something of herself behind that was very valuable.

MG: And what a gift to her to be valued herself at the end of her life. What do you think had led the doctor-- where had she lived--?

FS: In a little town in Eastern North Carolina. What her family told me later was the person who saw her had trouble with English himself. She told him about her sculpture and her visions from the Bible, and so partly he thought she was hallucinating. Instead she was talking about reading the Bible and Noah

and the Ark, Mary and Joseph and Baby Jesus, those are the kinds of things she made. She would make sets of things.

MG: By visions she just meant seeing the scene in her mind.

FS: Right, right. But he took it as hallucination, we think. There was no way to interpret it because she was certainly not demented at all. She was a very bright woman who just didn't have an opportunity. Some of the other people that I work with in rural North Carolina-- because we do a lot of outreach into Northampton, Halifax counties--we go there, but then we also have telemedicine, which is two way television into these rural areas. I see a fair number of people who are frail, older people in nursing homes, and usually we tape them and give them the tape of their lives. I've gotten lots of letters from families after they died 'I didn't know dad did this,' or 'I didn't know Mom did that' kind of thing. But I think being able to review your life and think about it, puts it into an entirely different perspective. Things that bothered you this week, ten years from now look entirely different, or fifty years from now. People have themes in their lives that they like to go back to and emphasize, which are always, I think, very important to listen to.

MG: What kinds of themes?

FS: Most often it's family and family relations. I'd say that's always number one. And community, where they are. Work, for men particularly, usually is very important. Many of the older people here I think, the fact that they survived the depression, the Second World War, those kinds of major or world events and came through, remain very strong themes in their lives. Over the last three or four years, I've seen a number of people from World War Two who are now aging--seventies, eighties. Many of them haven't talked about that before. They've carried a lot of that with them, and the ability to talk about that and cry about it and sort of put it into perspective and talk about the buddies and those that came back. Maybe they've kept contact; maybe they haven't; 'maybe I'd like to call them,' those kinds of things.

MG: You say that's over the last few, did you say weeks?

FS: No, last few years. I've seen people whether they were in a nursing home or in the clinic or whatever, the experience of that. Probably my all time favorite and a person that will never leave me I guess; I think about her every day. I'm going to use her name because I think it's all right, Martha Tippet who lived catty-corner in the house here. She died six years ago at 97. She was in her eighties when we

moved here. She was widowed and lived alone and was an unusual woman in that she had a master's and had taught in some of the New York private schools. Her husband was James Tippet, the writer of children's books, and on the faculty of the university. So she was a very bright self-assured woman who had had a lot of very different experiences than the people that I've been describing to you from the rural areas. I guess one of my favorite things that I have in this house is that when she was ninety, she wrote the first ten years of her life and gave it to me as a birthday present. She starts with being found in a rosebush in Kentucky, which is what they always told her where babies came from. It's called The Kentucky Babe. She describes the first day of school; the books they used; the games they played; and all that sort of thing; and the turn of the century, December 31, 1899, what the ceremony was like; walking home with her sister holding her hand; and the things they sang, which were religious songs, et cetera; and singing in the new century. Then later on when she went to college, she marched with the Suffragettes. When the women's museum opened in Seneca--that was I guess maybe four or five years ago, I'm not really sure--I went up because I felt I had to go do that for Martha. I've had to close that gap that part for women's rights had been closed or at least recognized in a formal kind of way. So it was a very exciting time for me because I was able to read about many of these people that she had talked about to me. I could've done it otherwise, but here they were in a museum with photographs in a way that I hadn't seen them displayed before.

MG: It sounds like she had an amazing life. Was she interested in reflecting on it of her own initiative or was that something that you sort of brought out in her?

FS: I think she would, but I think you have to start the conversation. Then she could talk non-stop, if you brought up the subject. She was here--she became a grandmother for my children because my mother had died young and John's mother had had a stroke very young. So they basically never had grandparents as such. She was here at dinner one night, and my older daughter who was a high school student brought up the fact that in history that day they had discussed McKinley's assassination. And Martha said, 'Oh, I remember that well.' And for the next probably thirty minutes she described in detail what she remembered about the assassination, the funeral and all these things. Jackie went back to school and told the class the story the next day. Her teacher called me and said, 'Your daughter has the most vivid imagination and storyteller skills.'

MG: 'She claimed that she'd met somebody who had remembered this.'



FS: Right. I said, 'But it's true!' He couldn't believe it; he was so delighted. But she was almost ninety-five and remembered all these details. She was very sharp until the last year.

MG: I'm interested that you say that both you and your husband had a parent who died relatively young. Could you talk a little bit about that?

FS: Sure. John's father, I never knew. He died in his fifties of a sudden heart attack. He was a first year medical student when his dad died. So I never knew him. My mother died, well I shouldn't say so young; she was about sixty. Everyone in my family on both sides had died of heart disease for three generations, except my mother. My mother had some surgery and got a blood transfusion. That was in the days before they test for hepatitis. She picked up hepatitis and died from hepatitis. So it was a liver disease, which was a slow several months kind of dying, as you know, the anxieties and the confusion, and all that.

MG: How old were you then?

FS: I was thirty, thirty-one. So I wasn't a child don't get me wrong. I may have given you that impression.

MG: No, but still relatively young.

FS: Right, right. My children were just little toddlers. They were very small.

MG: So they didn't remember.

FS: They didn't really know her.

MG: What do you remember as being your first experience of being with someone when they were dying?

FS: The first--I'll relate two experiences to you. The first time I ever saw a person who was dead was when I was probably about four or five. TB was still rampant then. I'm a dinosaur. But people were still dying of TB. I remember my mother taking me to--the caskets would be brought and the bodies would be brought to the homes--to a person's home, who was a young woman, probably in her twenties, who had died from TB. That's the first time I had ever had that experience because I had lots of questions about what this was. I didn't understand.

MG: Death.

FS: Right, exactly. Why the person, did they need to be fed? How come they were in that box? All those kinds of things, I remember having all those questions. The first person that I was ever with that died was at the Mass General when I was a graduate student. I was probably about twenty-two. The person--I didn't realize what was happening at first. I ran to get their families because I knew that was important for the family to be there who were in an adjacent room as I recall. I knew something bad was happening, but I didn't really understand. So I went running for the intern and for the family to come in the room. The person had responded to me when I'd seen them before, and all of a sudden it was very different.

MG: What was different? Do you remember?

FS: Well, the response wasn't there. The color had changed. The breathing had changed, et cetera. Sort of the symptoms that one sees. I remember being very upset afterwards because I kept thinking there must have been something that I could have done. Not realizing that there probably wasn't. I remember talking with the intern afterwards. Asking him if I'd gone in earlier, if I'd yelled a little louder for you or whatever, would it have made a difference and he said, 'No.'

MG: So then did you, when you got the family, did you go back in the room with them?

FS: I stayed with them.

MG: What was that like?

FS: Well, I remember just feeling totally empathetic to them because you feel that there is nothing that you can do to change it. Yet you feel so sad for the family because you see the anguish and the pain that they are going through. I think just the sudden jolt of this happening because it was not expected. So knowing the person was ill but then the fact that they--it's not often. I think they threw an embolism or something. I'm not really sure.

MG: But more often the situations you've been in, it's been a matter of waiting for the person to die?

FS: Right. Another experience--when you talk about that--I'll tell you about experience that I had in Hospice. Because I think people sometimes, I think they have control over when they die. The more I worked with Hospice, the more I became convinced of that. That they will stay for an important something to happen, to get through a holiday a birthday or son or daughter to arrive from some distance that they

haven't been able to see against all odds. I'm thinking of two situations that I worked with in Hospice where I thought this was very vivid. One was in rural Durham County. The person who had been really, we thought for days was going to die. Her family were hoverers. They wouldn't let her sort of, well I guess, take a deep breath alone. You see families like that. That's their needs and that's what they need and you help them as best you can, but you also want to help the person with what their needs are. But, a family member had died in that family. So the family wanted to go to the funeral. So the nurse and I went to stay at the house so the family could go. The night before this person had suddenly felt better, had sat up, had drunk a cup of tea, had a great conversation with several members of the family. The family was not out of the driveway until she died.

MG: She wanted to be alone, or with you all.

FS: Right. It was like they had to leave for her to let her body release itself.

MG: Amazing.

FS: From the spirit. We had to call the funeral home of the funeral and tell the family that, in fact, she had died. So that was one example. So another example of when people need to say rectify situations before they go to say they're sorry. Another person I worked with in Durham County was dying of, as I recall, lung cancer with metastatic disease. He was a man not sixty, in his late fifties, and had a couple of daughters in their twenties. He lived in a rented room with very little resources. But his daughters had been very attentive to him and came. Worked the shift and took care of him et cetera. I would go visit with him and talk to him, and we went fishing and did all these things in his life. And he hung on and hung on and hung on and one day I said to him, 'Mr. So and So there seems to really be something that's keeping you here that you can't let go of.' And he looked at me and smiled and he said, 'There is.' And he said, 'I need to see my ex-wife.' She had remarried years ago. He had abandoned his family when these children were three and four years old. And he said to me--

MG: But yet he had a relationship with his daughters now.

FS: No. Basically he had not maintained until very recently regained a relationship with his daughters, but here they are giving him all this attention and care and love. He said, 'But I've got to see their mother.' And he said, 'Because I used to drink all the time. I walked out on the family. I didn't provide for them.' He said, 'I used to beat her.' I can't die in peace until I tell her how sorry I am for what I

did and the life I led.' So I talked to the daughters, and with some reluctance she came a day or so later. They had two or three hours to themselves just to talk, and he died that night. It was like he could let himself go when he had settled that account with his wife. So I think that's another example of people needing to do these things because I think you die easier. The relatives feel better afterwards. There's not such a tough bereavement situation because I think when you leave, when there's a lot of guilt or anger, and wishing you had said things, it makes it much harder to deal with afterwards.

MG: Have you seen situations where someone like this person who was dying made an attempt at reconciliation and the family members were not receptive? Sort of the opposite of the story you just told.

FS: I know that's happened. Sometimes--I used to think I had failed when that happened. But then, I think, as I have gotten older and more experienced, I've realized I can do as much as I can do, but the other person has to come their part of the way too. I can facilitate as much as I can, but there has to be the willingness on the other person's part. Some of the things that I have done with people, I used to run a support group back in the eighties even when I was a student, which in those days was unique to run bereavement groups. Now they're on every corner practically. But I can remember many of the people that I worked with in that bereavement group had such situations happen to them. They weren't handling the deaths well because of things like that. We used to do a lot of writing in the support group that they would take to the grave and read it to the person and ask whatever, or we'd role play, those kind of things. Because I think people need to let go, need to turn it loose, because if you don't it eats your insides out.

MG: It's a lot easier to do it before the person's gone, but it's still possible afterwards.

FS: Absolutely. Not everyone has that opportunity. Because it could be an accident, unexpected, whatever or that they may have been a reason that they were unable to do it.

MG: Have you ever in your work either with Hospice or at UNC in the clinic--it sounds like a lot of the stories you're telling, the families are open to your involvement, are appreciative of the help that you provide and the facilitation that you provide. Have you ever encountered families who were more resistant? If so, then how do you handle that if someone were to view you as intruding in their private affairs?

FS: Sure, there have been people like that. Some people will not ever let anyone-- there are situations where not anyone from the outside can be a part and help facilitate. The person may not want to

resolve it. That's their right. Sometimes I may not be the person. It may be their friend or neighbor down the street. It may be whatever. Different personalities work with different people in different ways. I think if I can't, and I can offer help with finding someone else that's more appropriate to deal with it, that's fine too. One glove doesn't fit all. It's like a tree; all the leaves are different. You have to respect their differences and value systems and belief systems and that sort of thing.

MG: How do you see your work? Do you see it as a calling, like a religious calling, or a personal desire or vocation? How would you articulate that?

FS: Golly. That's a tough question. When you ask me about a religious calling, I'm not a churchgoer. I've always admired people for whom going to church gave them solace. It's never been that for me. I like to think that I'm a decent person. I know I care about my fellow man. If you use it in the term of formal religion, no. But I think I am a very spiritual person. I guess I've always felt, and certainly it doesn't make me better than anyone else, that every person is unique. They have their own contribution to make. If somehow I can be a part of enhancing that, that's marvelous. That's why I love my students so much. I have graduate students. At this point, when you've been in the profession as long as I have, and I have students all over this country. When I go to national meetings, I run into my students doing this,-- and at Christmastime, I probably hear from hundreds of them-- I've had a new baby; I've gotten married.' Those kinds of things. That gives me a great thrill because I don't know that I've had much to do with it, but the fact that the person maintained the relationship, or felt the need to is a very important thing to me. My family is extremely important. I use family loosely, not necessarily my blood relatives but community environs as being crucial to quality of life.

MG: So all of those things are part of a value system. It's not necessarily formally religious.

FS: Right. I call it sort of an overgirding of spirituality. I don't know if other people would particularly describe it that way. For me, that's what it is.

MG: So as you're spending time with people and they're dying and facing the question of 'where am I going,' how do you approach that?

FS: Well, depends on the person. I'll give you my example, with some people I've used for whom religion was very important and who felt very strongly that they were going to meet their relatives when they died. Many of them--sort of a clue when they are dying is that they begin to have visits from relatives



who have died, and it gives them comfort. Some people are afraid to listen to that. I always explore that if the person wants to talk about it. I've been with people when they were dying. I've held their hands and say, 'Yes, I'm here holding your hand.' Or 'So and so is here holding your hand while you cross over to meet,' whoever they've talked about, because I feel like that's a great comfort to them, and I have no reason to believe that that won't happen. I have a tape-- the North Carolina Humanities Council gave a grant to some of us to do some tapes of people who were dying. I should give this to you if you want it for the library. I interviewed a woman who was dying. It's a videotape--who's in her seventies from rural North Carolina. She felt very strongly about this. That's what sustained her through her final illness was looking forward to seeing her husband again. Many people who are older with long relationships with spouses, this seems really important to them. It's a belief system that enhances their quality of life. Talking about that relationship and what they expect later and how it may change, et cetera. I've always worked on interdisciplinary teams. I've never soloed. So I'm accustomed to having other disciplines around. I've thought over the years as I've worked, so many of these people have such supportive and loving attitudes, sort of very strong feelings of spirituality. I get very upset when I hear physicians criticized. Certainly I know some of them need to be criticized. But yet I see it from another side. I see it from the side in the back room when they work with people, and how much they care, and how frustrating it is for them when they can't make things happen that they want to and so forth. Many of them as they get older--my husband graduated med. school in '59. He told me that all the way through medical school that if a patient died, you failed, which is a really heavy burden to put on people. Fortunately things have changed now. Hopefully medical students and other students are getting the fact that it's another stage in your life that happens.

MG: That dying is a part of living.

FS: Absolutely. It's the same as birth. It's the other end of the spectrum. Hopefully, we're making some impact on that. Things have really changed. When I think about starting from the sixties, which I told you about with the kidney machine; into the seventies as more technology developed; and into the eighties as we got into court suits about people needing to have technology and things removed. Until I think now we've a long ways to go. Certainly we aren't there. As you know, every state has a different law relating to the end of life. I guess politically it's such a hot potato that they wouldn't dare develop a national standard. Do you want me to speak to that?

MG: Sure.

FS: It must've been probably four or five years ago, when the political climate was slightly different than it is now. Henry Waxman of California was interested in having a group of us who had gone through the courts to remove technology for family members come together in hopes of looking at a national standard. Politically he found that he couldn't do it. There was too much. There was simply too much controversy and variations in belief systems so that a national standard probably would not be possible now. You've seen the laws passed in Oregon; failed in California. I guess it was last week or something, I got a phone call from Senator McCain's office in Arizona in which he's put back through the legislation to fund the Older Americans Act. I didn't speak to Senator McCain; it was an aide who was wanting to know what the issues are on aging in the country because he was looking at that. And I talked again at them, because I think maybe we ought to start looking now again at some of these issues in training students more vigorously and education and the society. We need to have much more discussion going on about end of life issues, respecting people's values and that sort of thing. They're quite interested in looking at it again. I don't know if he'll begin to work on some sort of legislation for the next Congressional session or not. I was told I'd hear back from him.

MG: So even though generally now families have a good bit more freedom in how family members who are dying, the treatment, and control, it's still not a settled question?

FS: Right. Some states don't have living will legislation. All states have durable powers of attorneys in which they interpret that as a substitute judgement being made for the person. North Carolina probably has one of the most aggressive laws in the country thanks to the Medical Society and the Bar Association because we have the health care power of attorney which clearly lays out the person's substituted judgement if you are unable to and the living will. Perhaps it could provide more clarity about some things. It does have permanent vegetative coma covered et cetera, but if you go to Connecticut as an example and contrast. Connecticut has a living will law, but you can't remove food and hydration. The states vary by what's acceptable and what's not acceptable. Sort of related to that, I'll tell you a story about Connecticut and why I bring it up. I guess it was about five or six years ago, a person who was an executive from the Triangle called me. He talked to me about his mother who had a dementia and who had a massive stroke and was in a permanent vegetative coma and had been for three years in a nursing home in

Connecticut. The family was well off; they could afford to pay the \$45,000 a year for the nursing home, but they felt this was ridiculous. They felt this was cruel and unusual punishment. The gastrostomy tube had been put in after she had her stroke. Even though he had power of attorney, no permission was granted. He did not give them permission. So he asked them not to give her antibiotics if she got respiratory infection; not to give her a flu shot and all these kinds of things so that she perhaps would develop the old person's strain of pneumonia and die. It didn't happen. With this tube she just kept surviving. He talked to me about it. I said, 'I'll tell you what I would do is bring her here because the tube can be removed with the statute in this state, and she'll be here. You can be near her.' et cetera because there was not much family in Connecticut. So I found a physician, a very much-loved internist here, and sent him to see him. He agreed that he would remove the tube if they brought her here. So these are people with means, so they sent the jet up and brought her to Chapel Hill. What happened was very interesting because they really gave him a very hard time to let her leave Connecticut. The Attorney General of North Carolina, I understand, got a phone call from the Attorney General of Connecticut questioning whether or not he was bringing her here to kill her so to speak, which was ridiculous because basically she was dead already. But he did bring her. So he wanted to wait a little bit before they removed the tube to see if there was controversy or something. She basically picked up pneumonia and died with the tube in. So it solved the problem. That experience was so negative that he actually comes to my class and talks because I like people to be able to--he is very open about discussing it and very articulate. He says how different his memories of his father is from his mother because his father developed acute leukemia and died in two weeks and had played golf the day before the diagnosis was made,-- Maybe not the wildest game of golf ever. But yet his mother lingered basically dead for three years.

END OF TAPE 1, SIDE A

## START OF TAPE 1 SIDE B

MG: This is side B of the first tape of an interview with Florence Soltys. We're in Chapel Hill, NC on August 28, 1998. The interviewer is Melynn Glusman, and the tape number is 82898-FS. Since we were talking at the end of the other side about some of these policy issues in terms of life support and right to die debates, before we started the interview, you were telling me about your family's personal experience with that. I wondered if you could talk a little bit about that.

FS: Sure. I'll be glad too. It certainly was probably three of the most difficult years of my life. My brother was a professor at University of Rhode Island and Brown. He and his family had lived in Rhode Island for many years and had two children. Marsha, my sister-in-law, was a very quiet private person who played the piano beautifully, gardened well, and was a stay-home mom and was talking about going back to school for a masters. She had an undergraduate degree in chemistry. She was a runner. She ran five miles a day, very trim. Myself being more than a little overweight, she would always tease me et cetera. She had run that morning. This was in January of '86, and she and Glenn had gone to the grocery store, and she developed this terrible headache that was unbearable. The hospital was within three or four miles. He drove her over, and what was interesting was that that hospital had just gotten a CT scanner within that week.

MG: Wow.

FS: So they scanned her and realized that she was having a massive cerebral aneurysm. Of course, they had to medicate her because of the pain, and very quickly she was unconscious.

MG: Because of the medication or the stroke or both?

FS: Probably both. I don't know. I assume it was both because the bleeding was so ferocious apparently. What they said was they called the neurosurgeons at Brown/Rhode Island Hospital, which was probably about thirty miles away at Providence. They sent her blaring there. My brother followed. They did probably about seven or eight hours of surgery, knowing that the percentage of her surviving the surgery was low. Here was a woman who was forty-five years old, very active, involved. So you want to do that. You give her every chance.

MG: With young children?

FS: The children were high school. The daughter was fifteen, and I think Brian was seventeen, so teenagers. She survived the surgery and came out on total life supports. There was a lot of hope among all of us that she would come out of it. Also, reality told us that probably not, but hope springs eternal. This was just such a shock. After six weeks went by, we began to talk. The last visit here, which had been the summer of that year, Marsha and I had talked. She was talking to me about--she read a lot; she was a great reader. She had read a lot about what was the young lady that was the first person to get the respirator removed in New Jersey.

MG: Karen.

FS: Karen Quinlan. Thank you. One of the things about aging is it flies by, but often it comes back. Karen Ann Quinlan, she had read about her and she was talking to me about her in relationship to Hospice. She said, 'You know,'--they had taken her off the respirator, and she had survived because she was tubed and fed for several years later. She said to me, 'You know, I think that was so cruel that they did that.' We talked on about people's rights, et cetera. Then she said to me, she looked me straight in the eye and said, 'If that ever happened to me, you wouldn't let them do that to me would you?'

MG: Put her on life support you mean?

FS: She said, 'If that every happened to me, you wouldn't let them do that, you wouldn't let them do that to me would you, because I think that is so cruel.' I said, 'Of course not.' Never thinking that some day I would have to live with this, with making a commitment. So I told my brother about it because it was really beginning to eat into me that she had been clear. He said, 'Well, you know there were no'--There was nothing in Rhode Island at that time, no legislation that she could've signed other than verbalization to have her wants expressed. Who at forty-five when you run five miles a day thinks that you're going to have to make a decision like that? So, anyway we talked about it. Her father was dead, but we talked with her mother and the children, and my brother met with the neurosurgeons and decided to ask them to remove the respirator.

MG: But not the feeding tube?

FS: No, the feeding tube had been put in. At that point they were still doing physical therapy and so forth. We decided that if she couldn't survive off of the respirator that maybe we should let her go. What we thought was, this probably would happen and people were prepared for it to happen. But she had



enough brainstem function to continue to breathe, and so she did. Shortly thereafter--she's in intensive care at Brown University--shortly thereafter, she developed an infection. So they had to go back in--the fluid was not draining-- and put in the shunt to drain the fluid. When they did that it became extremely apparent how bad the damage was because her head caved down in the cerebral area down to her eyebrows. It was quite clear there was no cerebral functioning; only the brainstem was left that kept her cardio-vascular and respiratory system et cetera working. She stayed in intensive care at Brown for seven months, and even though my brother was a professor there, they said, 'We just can't. She's chronic. We can't keep her in an intensive care bed,' which we understood. A nursing home wouldn't take her. She needed intensive nursing care, need to be turned and everything. No response with anything. We took music in; the children did all the things, visited her everyday. There was no response.

MG: Ever from the moment she--there was never any response after the surgery?

FS: Before she even went to Brown. Well she was already unconscious when she was transferred to Brown. After that there was never anything. In the meantime, time marches on. What do you do with her? So she was put in General Hospital in Cranston. It's a big campus like Dorothea Dix is the best way I can describe it to you here, except there is a hospital for people that have severe illness, physical illness. Many people have had massive strokes, a whole variety of things, non or low functioning. On that grounds is another big mental health hospital and prison et cetera. It's the big sort of state thing. She was in a--she loved the ocean--she was in a private room which had a magnificent view of the ocean. Every time I would go in, it would bring tears to my eyes because I thought how much she would enjoy this. If only she could see and take in how well she was living. It was on the upper story of the hospital. In the meantime, the bills are clicking away.

MG: Was the insurance paying for her?

FS: My brother had Blue Cross-Blue Shield of Rhode Island. Any time I read the policy, I knew they were going to pay while she was at Brown. When she got transferred, when we read the policy, we could see no way. After a year passed, two neurologists came from New York and Boston and looked at her and said, 'There's nothing there.' So my brother decided after we had talked a lot, he asked the physician if they would remove the gastrostomy tube.

MG: That must have been a very difficult decision.

FS: Yes. And the physician said that he had no trouble doing it, but he had to have permission from the hospital administrator. So the family asked for a meeting with the hospital administrator. When you got there, the attorney general was there.

MG: Of Rhode Island?

FS: Um hmm. Mr. O'Neil was there, right. Mr. O'Neil said that we could not remove the gastrostomy tube because that was murder. There was a law against it in Rhode Island. So my brother said to him, 'I understand that it is a state hospital. We'll move her to another hospital to have it done.' He said, 'You can't remove her from this hospital.' He then said to us, 'If you remove her, I'm going, as chief law enforcement officer of Rhode Island, I'm going to charge the family and the physician who does it with first degree homicide.' So at that point, we had a tough decision to make. So we talked and decided that, yes, we were going to do it, and if we all went bankrupt because at that point we were thinking we were looking at the Supreme Court, that we would do that. That that was a value that we shared.

MG: And that she'd expressly said that she wanted.

FS: She had expressly said, there was not question about that. That this was sort of the last act that we could give her of love was to release her from this. So then what do you do about an attorney? So my brother is a workaholic. And certainly not a women's--he was very respectful of women but it certainly wasn't that he would have gone out of his way to support a liberation kind of movement for females. But we talked about it and I said, 'If we could find a good female attorney, we'd do well.' We found someone who was thirty-six years old, had never tried a major case, and who--but what was so good about her was that when she had been a law student, her husband had had cancer. The two of them together had made a decision to stop treatment at a certain point. She was far enough away in years to have gone through the bereavement, but she understood what it was like. He had not been on machines so that was not an issue for her. So she took the case.

MG: What made you specifically look for a woman lawyer?

FS: My feeling was that if they had the right kind of experiences, they would be very empathetic. They would have the law in one hand and the feelings on the other, which I thought was very important to bring together in this situation. I guess, I thought you had to have both to do a great job.

MG: And you thought a woman would be more likely to have that ability to empathize?

FS: So prejudice on my part. I'm on the other end. But I was proven true. We filed in Federal Court because we were suing the State of Rhode Island and the hospital administrator. It was an arduous time. The judge that we drew was Francis Boyle. I don't know if you remember who Mr. Boyle was or not, or Judge Boyle. He had been the attorney for the Right to Lifers, national attorney. You don't have a control over the judge, and it makes you sweat blood, but he was a straight shooter. Many people feel he gave the best decision that's been done yet in a case like this. There had been a number of cases in states, like there had been a case in Massachusetts, two in New Jersey et cetera, the Jobe and the Quinlan and the Brothy in Massachusetts. So there had been state courts but not Federal. So this put it on a different level. It, of course, began to make the newspapers pretty quickly. The press was quite interested in the whole thing. We began to sort out who would enter Friends of the Court petitions to support us. A lot of organizations did. Some supported us very quietly in the background; it was such a hot potato politically that they were nervous about openly supporting us. I guess one of my great disappointments was that the Hospice wouldn't support us.

MG: Why was that?

FS: Because some people on the national board objected to removing food and hydration at that time. Remember this was 1985.

MG: What were some of the organizations that submitted amicus--?

FS: The Bar Association, some members of the Medical Society, the Episcopal Church. But what was interesting is that Rhode Island was ninety-nine percent Catholic, and we felt that that was important. My sister-in-law had been raised as Catholic and certainly didn't--she would go to church on major holidays, but that was it. So we asked the Bishop of Rhode Island to enter a Friend of the Court petition with us. We actually waited on filing the case hoping to get that. After waiting for some time and not getting it, we went ahead and filed the petition and didn't hear anything. We had never met the man. On the Saturday afternoon, he held a press conference after we had filed the case for some weeks, and said that he was entering a friend of the court petition because he felt what we were doing was right. He had investigated it, and released a pretty scholarly kind of reasons for why and thinking through and so forth. The man later really took it from a lot of groups, Right to Lifers and from many other priests and cardinals

et cetera. He basically in many ways did this on his own and took the responsibility and took a lot of heat for it. So he to me is one of the heroes of this, and I have never met him.

MG: What was his name? What is his name?

FS: Genevie. Bishop Genevie.

MG: I'm not sure if you said, maybe you said your sister-in-law's name.

FS: Marsha Gray. Marsha Victor Gray. V-I-C-T-O-R. My brother's Glenn Gray. Some people got involved and others didn't. Hearings and things began to heat up, and more and more media was there. We were very staunchly supported by the media. There were times in this country when there'd be three and four editorials in one day supporting our position; so I never felt that they were not very fair. In fact, maybe they even tilted in our favor. However, the Attorney General and hospital director were press conferencing all along and making these outlandish kind of things. We never spoke to the press. We did it privately, but never held a news conference or anything. They were doing it almost weekly and basically just crucifying us. My brother decided that that was not going to be the tact we were going to take. We would privately talk to reporters or whatever, but we wouldn't press conference. The first clue we got about Judge Boyle was he slapped an order on them that they couldn't hold any more press conferences, a gag order. As we sort of moved along, he stopped it. Other things that happened are they bussed in Right to Lifers to the hospital by the busload, who picketed.

MG: The hospital administration did?

FS: No. I don't know who was responsible. I don't know that they were, but somebody was because they felt that this was the equivalent of murder. They plaqued murder. When you'd go in and out of the hospital, they would be picketing. We were recognized, so they would scream 'Murderer' in our face.

MG: As you were going in to visit Marsha?

FS: Right.

MG: How awful.

FS: So this was hard. It was hard not to say something back, to look straight ahead. They called my brother's house. He wouldn't change his phone to an unlisted number; he said that he wasn't going to do that. He said that there were certain things that he was not going to do, and that was one of them. They had a tape recording that they made, which sounded like a chain rattling on metal and then like someone

scratching a blackboard, and it started out very loud saying 'Murderer.' Then it kept getting lower and lower and lower unless you hung up the phone, and it would be repeated every time it was called.

MG: Oh my gosh.

FS: That was hard to take sometimes. It would give you nightmares.

MG: Did that sort of opposition ever for you or for him, did it ever make you question your decision? Or did it make you more steadfast?

FS: It made me more determined to see that her rights were followed. It hardened me.

MG: What about for him? Do you know if he ever--

FS: I think it did for him too. My brother continued to teach and carry a full load at the university. He never stopped. But he visited with Marsha every day. Meantime Brian--they had their twenty-fifth anniversary, and Brian graduated school, and Karen moved up to graduate school. All of these things were happening, and we were telling Marsha, but there was no recognition or anything. In the meantime, the bills were clicking away. It was over \$500 a day in the hospital, which is a lot more money now than it is in those days. Also the lawyers fees were clicking up. We thought that Linda McDonald, who was the attorney, would be very reasonable with the fees, but on the other hand you know it was going to be over a hundred thousand easily. Obviously my testimony and my statement of what she had said to me was very important in the trial. I think that was one of the things that was very hard because I knew that my testimony was going to be in great part what the decision was going to be made on. That, I could say I was responsible.

MG: Was it hard because--

FS: I think it was just hard saying it.

MG: Yeah. That this is what she said, and I'm going to stick by it.

FS: Right and because I believe this is right. But it's still hard to say. Do you know what I mean? It was painful. But anyway, this dragged on for three years. The decision was by Judge--my brother was-- I was teaching a class so when I came home that evening, I got home at eight, I had a phone call to call him as quickly, a recorded message to call him as quickly as I could. I called him and he said that he was teaching a class and got a phone call saying that would he please be at such and such a place at 4:00, that Judge Boyle was rendering his decision. He rendered his decision and he said that-- He quoted the Wade



Roe case throughout the decision, that's really almost every page. He said that a person irrespective under the right of privacy in the Constitution, the First Amendment, has the right to privacy and making decisions about whether they'll accept or reject treatment, and that if they can't, their family has the right to make the decision. The burden is on the opposite party to prove that the family doesn't have the best interest. They would remove the gastrostomy tube in the hospital, but if we chose to move her that we could move her. But if we chose not to, that he was ordering them to remove it within thirty days. So we began to look, because of the hostility, we began to look at where we'd move her. This little community hospital where she had first gone is within just a few miles of their house. My brother received a phone call--most hospitals wouldn't touch it. It was making the headlines of the paper every day at this point, in the national news et cetera. This surgeon called my brother from this little hospital and said he'd like to have lunch with him. He met with him, and they talked. He was a surgeon who was much loved in the community who was one of these physicians that when you saw his face, you felt better. He said after he met with Glenn and he called him the next day and said, 'I've thought about it.' And at that point, we still didn't know if the attorney general would charge the person with murder that removed the gastrostomy tube.

MG: In spite of all this?

FS: In spite of the court. Right. No one knew. There were lots of questions. We also didn't know if they were going to kick it to the Supreme Court. We started preparing to go the Supreme Court. So he said to my brother that he would like to move her back to that little hospital in her own community, and he would remove the tube. He would take the risk of being charged with murder. He said, 'But I must prepare the hospital for this' because we also knew that there would be lots of pickets. This is a small place. What he did was, he met with the board of directors, and they met with every shift in that hospital and asked them if it would be acceptable to bring Marsha there after they removed the tube to let her die. We thought it would be about a week, but it wound up being ten days. In fact, no one objected except a person in the record department and he said, 'It's the family's decision. For me it's not right but I won't stand in the way.' So we had total agreement with us for this little hospital to take her. This beloved surgeon would remove the gastrostomy tube.

At the end of the thirty days and at the time, which was like six o'clock in the evening, we knew they hadn't filed the Supreme Court, which was what we were waiting. So my brother arrived in his car,

and met the surgeon at the area of this big hospital where the loading dock for supplies coming in. The ambulance driver didn't know where he was going because they didn't want the media to know because of the heat. So he arrived with my brother, they went to Marsha's room and loaded her on a gurney and started to take her out of the hospital. The directress of nursing arrived and began to throw an utter fit and my brother said, 'We are taking her out because now the court-- We have a right now. The thirty days are up.' A middle aged black woman who was a nursing assistant came in and helped them load her on the gurney. Apparently the directress of nurses threatened her and my brother said that she put her hands on her hips and said, 'I'm doing this because it's right.' So they took her out and got her in the ambulance. On I-95 between the two hospitals, the physician removed the gastrostomy tube so that no facility could be charged, only he, if the attorney general decided to, which fortunately did not happen. She was brought to this small hospital. All the nurses who cared for her around the clock were volunteers. Have you ever seen anyone who's been on a tube feeding for years?

MG: No.

FS: Remember that I told you that Marsha was a tiny little thing that weighed 124. She weighed over 200 pounds. You would not recognize her. She was not recognizable as the person you knew because you just get this very bloated, distorted look. When the gastrostomy tube was removed, she began to get rid of these fluids. She had played the piano as I told you earlier beautifully. Her hands had been in contractions. Her hands began to open, and you could see her fingers again. She still had the leg contractions of course and feet. But it was like her body began to relax because it knew that distorted, weird, grotesque kind of look was now becoming more of her as days passed.

Ten days, she survived. I think her cardio-vascular system must have been in excellent shape because of all her running and the fact that she still was young. We were all around her, around the bed, holding hands. My brother sat on the bed, when it was very clear, when she chain-stoked and we knew she was going. We were all telling her goodbye, and we'd be fine. She just quietly gave her last breath. There was no discomfort. At the trial, there had been accusations made about all sorts of contortions and all this that people go through if they are not fed and hydrated. I had seen it from Hospice and knew it wasn't true. Certainly it wasn't true with her. She was more like herself. If we covered the top of her head above her eyebrows, she looked like herself again, which was the first time in all the years that she had been ill. It

was a painful experience. I think our greatest act of love was letting her go. In a way releasing her body from what--it must have been terrible, if there was anything there. I can't imagine how terrible it was.

What are some of the other things I'll tell you about? Well, the Right-to-Lifers picketed and it wound up that pickets jeered them, so there got to be this confrontational thing outside the hospital, which we were given a private entrance so that we didn't have to face that.

MG: That's good.

FS: Coming and going. But in the Brothy funeral in Massachusetts, the firemen who had had the gastrostomy tube removed that went to state court in Massachusetts. Mrs. Brothy was a friend. They had come--. She had an open funeral. They had picketed the funeral and outside the church. We didn't want that. So we had a very private--all the arrangements had been made--a private service where only people that were invited could come. It was small and the police blocked the whole radius. People coming and going were checked with a list, which seems weird.

MG: But given the circumstances.

FS: Right. That's what we felt we needed to do for privacy. People asked me about the money. Shortly after her death, we received a bill for just slightly below a million dollars. Blue Cross/Blue Shield quietly paid the seven months at Brown and the last ten days of Rhode Island at the small hospital. But it was the in between, the state hospital, that the bill was there. No family had ever sued for the medical expenses when a person obviously had been given care that the family didn't want. So our attorney went to the hospital and told them that we were thinking of suing. So they reduced the bill down to not so many thousands that we couldn't sell property and pay it. Or my brother did; I didn't pay it. He sold some property that he had bought years before that he hadn't paid that much for in the area near the ocean and just paid the bill. I wanted strongly for him to sue because I wanted to establish a principal for people. He felt that with the years there that he just couldn't do it anymore, that he was worn out. What we did do was we sued for the lawyer's, for the court--all the legal fees. They were over \$100,000. That was quickly given to us because her constitutional rights were denied her. Apparently when that happens, there's not a question of that. The decision rendered that that was indeed the case.

So what have we done with this? Well, my brother with the ACLU and the Bar Association and so forth then began to really work rigorously and the legislative body of Rhode Island and got legislation

passed. That state now has good living wills and durable powers of attorney et cetera. So that was one outcome. To tell you what people in this country are like: we received letters from all of the country. People saying 'Thank you.' People saying, 'My husband has Alzheimer's. I'm so glad that we can know now that we don't have to have these things when the person isn't living anymore.' There was publicity about our bills. Some people wrote letters--it brought tears to my eyes: 'I live on Social Security which is \$300 a month but here's five dollars.' So my brother took a long time answering all the letters and returning all the money. Thanking the person for being so thoughtful. But it was overwhelming. People that you've never heard and you're surprised that they would take the time to do that. So it's very heartening when you think of humanity and people's care.

MG: Well, and to have that to counterbalance some of the hostility.

FS: I want to say also that the Right-to-Lifers have every right to express their opinion. I would fight to see that they have that right because I think that it's a really important principle that this country lives by; however, they don't have a right to make a decision for me and my family if we think differently. I respect their values. I expect the same courtesy back. So that's where I disagree with them. They also petitioned the court to become her guardian.

MG: I didn't realize that the Right-to-Life movement connected so closely with end of life issues.

FS: Oh yeah. Very much.

MG: One thing I wonder about for you and for your brother and for their children, when something like that happens, when someone is very suddenly stricken like that, a natural reaction is to have a lot of anger: why has this happened? Why did this happen to her? And then on top of that, to have all of this legal battle to go through. I wonder how--it's just an unusual sort of experience going through the long-term illness combined with the legal battles and then the bereavement process so long after the initial event.

FS: In many ways, you have to let the grieving process wait because for many reasons: one is because you don't have the energy to deal with the legal issues and grieving because it tires you out. As C.S. Lewis says in *A Grief Observed*. 'Nothing makes you more tired. I can only shave half of my face and rest.' Grief is that way. We had to put it on hold, because you had to muster the energy to deal with those decisions that were really hard decisions and not knowing the impact that it's going to have on you, your

family, et cetera not only emotionally but financially; as well as losing Marsha and what the future might hold. We were lucky; we were educated, middle-class. When I look at that and think how fortunate we were in many ways to be able to have the assets we needed to deal with this. I look at really poor people with a health care system that's fragmented, that's difficult to navigate and to understand, and to really worry about the fact that they can't pay for it. They'll become homeless as a result of this. We also face that fact that we could've become homeless out of this. Our children may not have been able to go to college. Those kind of major values that you put forth in your life may suddenly disappear. You realize it. That was difficult because we were facing that on a daily, unknown basis for a number of years while this case was in court. So it wasn't just a brief interval. It was a long thing. Yes, I was angry. You can probably still hear some anger in my voice.

MG: Actually no. That's why I asked the question.

FS: For a long time--well, I told my brother. This is a terrible thing to admit particularly on tape.

MG: Well, if you don't want--

FS: No that's fine. I remember telling my brother as we walked through the Right-to-Lifers going to the hospital. I said, 'I swear I want to just spit on them one of the days going in.' He was kinder than I. He would have the coolness. He would say, 'Oh don't you dare, it would be headlines. You just look straight ahead and don't hear anything.' But that was sort of one of the things that I thought of. I had some depression. I didn't get treated. Maybe I should've. I probably would've done better had I done so. But little things that didn't bother you suddenly became enormous things that made you angry. You know your life was in such an upheaval that it was difficult. For the children, I think, who didn't have peers to really support them, who hadn't gone through this. They were the people that I worried about the most.

MG: Anytime kids that age lose a parent, it would be difficult for that reason.

FS: Particularly Karen, the daughter, because she was at a very crucial age where she needed to have her mother as a mentor, role model. This was difficult. She's now, I feel, really coming into her own having gotten over it because it's taken a while; it really has taken a while for her to deal with it.

MG: She was fifteen you said?



FS: Yeah. She's twenty-nine now if I'm right in my math. I've seen her grow and begin to blossom now. Quite clearly for a long time, you saw the scars and how painful it was and dealing with it and decision-making and choices she made et cetera.

MG: Not having that support there from her mom.

FS: Right. Right. Well, my brother and I--my brother, of course, her father is still there and very supportive to her. And I was always available, but I'm pretty far away. During, going through this, I was flying up there on a regular basis on weekends. I did what I could do to help and certainly spoke with my brother via telephone every day so that we tried to support each other. The family's not huge; her mother was living; and she had a sister. But her sister died of an aneurysm three years after she did.

MG: You're kidding. Oh my gosh. Had that run in the family before?

FS: Her father died while he was square dancing in his fifties. We thought he had a heart attack but didn't do an autopsy. People wonder if that isn't what it was now given the two children. So we worry about my niece and nephew.

MG: Yeah, I bet. Is there any way to test?

FS: Well, we met with a neurosurgeon and he said that if it's a--probably nothing we can do anyway.

MG: How about your nephew? How has he fared in the aftermath?

FS: He's doing well. He's an engineer, has two young children, lives in California, and does well. You asked me how I managed it. I can tell you how both my brother and I managed it. We had illnesses afterwards.

MG: Huh. Serious?

FS: I had a heart attack and my brother didn't have a heart attack but developed terrible chest pains a year later and had bypass surgery.

MG: So your body really took on the stress.

FS: Yeah. Yeah. Yeah. I think maybe we're sort of people that express it through our hearts. Whatever, our bodies. I think I can directly attribute it probably--even though as I told you three generations of my family died of heart disease except for my mother--I think I can. The genetic factor was there, but I think the stress certainly brought it on dealing with this.

MG: I wonder both about your conversation with Martha--

FS: Marsha.

MG: Marsha. Sorry.

FS: No problem.

MG: You know, about her wishes were something like this to happen, and also about the fact that you already worked in this field and then to go through something like this. I'm not asking I guess what do you think accounts for that coincidence, but do these seem to be just coincidences to you or do you--?

FS: I think she had a lot of interest in the area and that's what fascinates me. Why she was so interested in the area because she was also reading a number of the Russian writers that wrote about death and so forth. We were discussing some of the readings she was doing and my older daughter particularly was close to Marsha and she used to go from Yale to spend the weekends with them a lot. I think Marsha would sit and knit, and Jackie would read to her from many of the Russian writers because she was obviously a graduate student in the language and talk about it. I don't know. I don't know if this is something that happened to prepare her to deal with this. I think she talked to me because I was close to her and because she knew of my work in Hospice, and this was something that was important to her. I'd like to think that she thought that I would carry through her wishes that I would see that what she wanted would happen, which I tried to the best that I could. It just took a long time.

Maybe I'll say too how this personally affected me and professionally. I think I've talked about personally but professionally as painful as it was, I think we grew as a family tremendously. I think I'm a better person from having had the experience, not that I don't need lots of improvement. I think I'm a better social worker. I think I'm much more empathetic to the families, that I understand better how it feels. Though I can't really walk in their shoes, I do know how it feels. I think it makes me a much stronger advocate for people's rights to make choices. To celebrate and value life with people. My brother changed. My brother had been a workaholic. He took time to spend with his family, which he does now as well. I think he has some regrets that maybe he hadn't spent more time with Marsha than he should have. He takes time to travel now, which he didn't used to. He takes his children with him. He's very active in the two grandchildren's lives. They're a great joy to him. If he were a workaholic like he used to be, he wouldn't

have taken the time to do these things. I think it impacted. I often tell people that I've never yet talked to a person who is dying who told me they had regrets that they hadn't spent more time at the office.

MG: Right. Right.

FS: So I think that that's something that certainly rang true in our family and probably a lot of families. It's looking at that and sort of putting it into perspective.

MG: But yet they're all different sorts of work. It seems to me that depending on the sort of work that you do, that at the end of your life you would be either more or less glad that you had spent your time that way.

FS: Um hmm.

MG: Do you think that there are good deaths and bad deaths and in between deaths or do you think there are just deaths and they're all different.

FS: I think there are good deaths. I think there are people who have lived and done what they wanted and who to the end remained in character as their lives have been. Often they are very happy to release themselves depending on the situation that you're in. I go to a lot of nursing homes, people who are older and with lots of problems. I must say it makes me very sad when I walk down a corridor and hear older people crying to die, wanting to be released from where they are. My thoughts are often, 'What can we do to enhance their life so that this is not so unhappy for them?' But they have to beg. Yet you can see young people on drugs, alcohol or accidental deaths. I consider drugs and alcohol a suicidal gesture; it's just slow and very destructive. But why are they so unhappy that they have to resort to this. I think that those are bad deaths, very sad because the person hasn't been able, because of whatever reason, many, multi-varied, to be able to be themselves and meet their potential.

Yet I guess my heroes and heroines are the older black people in rural North Carolina. I see a lot of them. They didn't have the opportunity to have an education. They've never had many things that probably that many of us value like a nice home and things like that. Many of them have never even owned a car, and they've worked very, very hard. And yet these are some of the most generous people that I've ever met. They value their families; they value their fellow man; their religion is a great solace to them, almost always. These are people that I think never really get celebrated. They're the people that I think really need to be celebrated and have an opportunity to leave their stories behind, to tell what it was

like to live through segregation. What it was like not to be able to go to school. What it was like to live in a shack in a rural area and you know the woman who cleaned five white people's houses every day for whole years of their lives. Did it when they were in their seventies still because their social security won't cover the cost that they have to buy their needs, to meet their needs. So I guess these are the people that I feel I work for at the university, who never had an opportunity to come to the university. Yet have more good common sense than many PhDs. And I'm not putting down PhDs. I just feel like these people are pragmatic. They're survivors, and they really care. One of the reasons that I love the University is I feel like I work for the people of North Carolina, and I feel like they own the University. Maybe sometimes we forget that, but I think their stories are what makes, and their lives, the state what it is. It's changing. It's changed a lot in the twenty-three years I've been here.

MG: When you go out to rural North Carolina and visit these older black folks, what do you feel like-- as a part of the university or just as yourself-- what do you feel you bring them?

FS: Well I--

END OF TAPE 1, SIDE B

START OF TAPE 2, SIDE A

MG: Why don't you just go on with what you were saying at the end of the last tape about the health care team that you're a part of.

FS: I go out to rural North Carolina with a health care team so that we go there for that purpose. I often feel my role is to really get to know the person and to humanize the situation. Chapel Hill has a sort of magic kind of way when you go into these areas because they feel like we have the answers. But I like to say to them, 'We don't have the answers. We're here to do something if we can. But you're here-- we take students with us-- and you're educating our students. You're here contributing that will continue afterward.' My students love going there. The other place we go is the prison, the McCain prison. That's where all the sick prisoners of North Carolina are. It's like a giant nursing home in a way. We've been working with them for two years, and I take students there as well. But that's an equally fascinating experience because quite obviously these people have committed major crimes and sort of what led to that. Many of them were ending their lives needing to deal with that before they die as another major issue. That's quite different. Poverty and no education I would say are the two common themes that come through. But that's not always the case, not always the case, but it's--my students really--it's a very sobering experience to take them there when we go.

MG: These are mostly your students in the medical school?

FS: We take interdisciplinary students. They're students of social work, medicine, PT, OT, so they're interdisciplinary. Each time we take a trip, we take an interdisciplinary student team with us. When we go up to Northampton and Halifax County, we have students from Campbell joining us in Pharmacy. Sometimes there's a Pharmacy student from UNC joining us too. Sometimes we have students from ECU joining us. Then a couple of years ago, over telemedicine actually, I had a social work student--in order to have a student placed there, because our goal is to have these professionals move there afterwards, if they're exposed, to upgrade the quality of the personnel in those counties. I supervised her for two years over telemedicine, so it's not necessarily UNC students, in order to get her to take a job there afterwards. So I think that's also another charge: what can we do to help bring personnel in that will improve and meet the needs of the rural communities? And what's happening in the rural communities is that the young people can't find employment. So they're leaving, and you're getting more and more people who are old.



MG: That are isolated.

FS: Isolated and needing care. That's right. Another issue of course in bringing personnel in and getting people to move there is their spouse can't find work, they're likely to be professional too. Education for their children. Salaries won't be as much and your living expenses won't be as much, but if you want to go to Europe or buy a car, it's always going to cost you the same amount. It is a deficit. The isolation of not having fellow professionals to sort of bounce off each other and be supportive.

MG: Earlier you were talking about some of the changes that have taken place in terms of elder care generally and sort of medical attitudes toward death and dying. One of the things you mentioned was an older philosophy of doctors not wanting to tell patients what was wrong with them. That has changed to some degree. Certainly people have more control over the treatment of family members and that kind of thing. What would you say, other than the things that we've already talked about, what are some other significant changes that have taken place in terms of the medical attitudes towards caring for people at the end of their lives?

FS: I think Hospice is probably had the biggest effect because the national movement of consumerism has really pushed that organization. So I think you have many situations now where you have people embracing the philosophy of Hospice, where it's palliative care and not curative care, when hope is no longer really there. I think the other issue, continues to be an issue, is adequate pain medication, and the ability of physicians to relate to that. I've heard physicians say, 'I couldn't give the person more because they'll become addicted' and they're dying. Well that's absurd.

MG: What difference does it make.

FS: Exactly. So I think there's a good bit of change in that. I think probably one of the things that maybe hasn't changed enough, I know hasn't changed enough, is helping people, doctors, nurses, whatever, the frontline caregivers become comfortable with death. I think you have to be comfortable with your own death before you can become comfortable with working with people who are dying. So, therefore, I think in the education somehow, we need to help people reach this level of comfort so that they can be more themselves in working with people. I know a lot of people, when they're dying, feel that they are abandoned by their health care provider, that they don't stay with them. I think that is getting better but has a long way to go.

MG: Do you see changes in terms of the way medical students and social workers are trained and asking them to examine how they think about their own deaths and face that?

FS: I have my students write their own obituary the first day of class in my Death and Dying class. In the last class, they bring me their new obituary because I want to see how much they change over a semester in attitudes. For some people, it's absolutely startling. This is an interdisciplinary class. For others, it remains practically the same. I've been fascinated by using that to see what happens. They also journal for me because we get into some pretty tough cases which are videoed some of them and some of them discussion. A lot of ethical issues about that--bring attorneys in et cetera because I feel like they need to have this experience before they leave. We had our first dentist join us last semester, I think he enjoyed it. For my students, it was a really great experience. They're generally mostly nurses and social workers, but you get speech and you get PT and OT. We've never had a medical student take it. But the dentist--and public health people--was the first one either out of the dental school or the medical school to join in this class. I think next year I'll probably have more because of his having taken it. Consequently, he's going to go to work in a nursing home.

MG: I imagine that's real need. I hadn't even thought of that.

FS: Big need. It's very difficult to find dentists who will work in nursing homes.

MG: But you say you've never had a medical student in your Death and Dying class.

FS: I think they have a class. I think they have a class that is taught by Larry Churchill. Though it would add greatly to our class if we did because it would bring a perspective we didn't have. I think we need to look at a lot of issues at the university to develop more and more interdisciplinary classes. I'm doing a lot of that with my students in gerontology in which they work with residents in medicine and family practice and OT/PT. Nursing has basically been from Duke frankly. There hasn't been much from here because they don't have a very strong geriatric program. But I think it's really important for them to work together and understand what each other's strengths and weaknesses are and how they can gel a situation and work. I think probably if there's one thing in medicine that I think is really needed is that kind of experience, and that they look at the individual more in the functional quality of life way rather than a disease way. You can do that by their knowing their part of the social work, that they're dealing with parts of it, and the PT et cetera so that you give the person a different kind of overview.

MG: Rather than more of a rescue type mentality.

FS: Exactly. And chronic disease, I find that this is really important, which what most older people have. Hospice set the model for interdisciplinary because they that's a basic part of it. And the other thing that they did that I think is beginning to happen in medicine, but not nearly as far, is the patient and the family, the standard of care. The medical model has only seen the patient and families out here, something to put up with, and I think that needs to change too. It doesn't work the other way.

MG: We've been talking for a while is there anything else you'd like to say in conclusion?

FS: Not that I can think of. I appreciate you listening to me all this time.

MG: It's my pleasure.

FS: You've been very tolerant.

MG: Well, it's quite a learning experience for me.

FS: Well, thank you very much.

MG: This concludes an interview with Florence Soltys conducted on August the 28<sup>th</sup>, 1998 at her home in Chapel Hill, North Carolina. The interviewer is Melynn Glusman and the tape number is 82898-FS.

END OF INTERVIEW

Transcribed by Laura Altizer.