

JLMABCD@aol.com, 10/1/01 5:08 PM -0400, Fwd: writing

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From: JLMABCD@aol.com
Date: Mon, 1 Oct 2001 17:08:42 EDT
Subject: Fwd: writing
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Date: Sun, 30 Sep 2001 23:02:37 -0400
Subject: writing
From: "Judith Snow" <judiths@ica.net>
To: John McKnight <jlmabcd@aol.com>

Ok, Ok... I just don't have any time these days. REALLY!
Here is the submission I sent last week for a grant from the Canada Council.
I may be able to get \$10,000 CDN, (or less, or nothing), in about five months.

Love to Marsha and to you; Judith

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 CanadaCouncilpages.txt

16 pages

Excerpts from
A Quiet Voice
a book in progress
by Judith Snow

Why This Book and Why Now

Helpless! Needing help. Constantly needing help. Is this what defines my life? Such is the case for people labeled disabled. This perception, in our own eyes and in the eyes of others, becomes the framework of our lives.

I am a divorced, childless, 51 year old, white, Canadian female. I have been self-employed for fifteen years. I report on my yearly federal income tax a net personal income of about \$36,000 CDN. I am paying down my half of a mortgage on a venerable storefront in Toronto that we converted to a triplex. I have written a book that has gone into second edition.

These things would define my identity in my community - excepting that I also have Spinal Muscular Atrophy, Type II. Since seven months of age or so I have been quadriplegic. I am classified as severely disabled. I have as much physical strength as a new born infant. Without the assistance of several people and two specialized machines every day, I would die in hours.

Clearly I am helpless. Clearly I am not helpless. Both statements are valid, each in its own context.

Living this paradox, and reflecting on it, has taught me much. This book is about what I am learning about the nature of help, or support. I am on the trail to discovering the nature of support that helps without making a person helpless. I am discovering how a community can benefit from the presence and participation of individuals who typically get labeled disabled. I believe that my society, culture and planet can benefit from having a different vision of vulnerability.

As a part of this discovery I will set out my own experience of being a person who has this amazing opportunity of living such an unusual life. My book has two themes. The first and primary focus is on me -- who I am and what I am struggling with in a world that believes in "disability". My second desire is to present another view of difference - a view which makes the sort of situation I described above easier -- even desirable -- to foster and sustain.

Why this book? At the age of 51 I believe that my path in life is basically set. For nearly twenty years opportunities have arisen every now and then for me to take up a different interest, career or set of friends. Each time I have returned to my decision to advocate for inclusive community. I have a vocation. I have neither the will nor sufficient intuitive understanding to carry me onto another way of life. In that sense it is virtually ordained

that I will write these words since not to do so would be for me to deny the meaning of my own life to myself and those who know me best.

When I was six years old I remember my Father telling me that some US doctors were putting children labeled 'mentally retarded' to death saying that society should not have to bear the burden of caring for these children. Dad, explained that in his youth in rural England children with 'mental retardation' were able to grow potatoes along with everyone else. They were a regular, accepted part of his community. But children like me were killed. People felt they did not have enough resources to support someone who would likely not be able to grow food.

My Father's story was harsh. But that is not what I heard when I was six. I heard that I had enemies and that I had better pay attention. I heard that he and Mom were going against the mainstream and that meant they loved me and that we were all vulnerable - all of my family. I heard that the way to gain acceptance among strangers was to contribute to the well being of the community.

I asked my Dad why he was keeping me alive. He answered: "Perhaps someday you will find the answer." At the time I thought he meant the answer to why some people get Spinal Muscular Atrophy. For years I studied hard in school so that I might become a medical research scientist. By the time I was nineteen I was sure I was looking for the answer to why people are so mean to people they call disabled. I became a committed advocate. Much later I am joined with many others in the quest for how we might all live together and in peace with the planet.

In spite of my Father's story and my understanding of its importance disability has captured the meaning of my life more than once. I have allowed myself to settle for being someone I am not meant to be. Finding the road away from and closing the road to a life of incapacity are part of my journey. This book captures some what I have learned about avoiding servitude to "disability" and escaping its bondage when necessary.

I believe that there is something to be gained from altering our cultural interpretations "disability". When this vulnerability is recognized as a difficult gift, as a challenging opportunity, as a grain of sand in the oyster's shell, then a wonderful resource is discovered. I have seen this resource, when recognized and appreciated, stimulate great feeling and action among people and wonderful resilience in community. This book is about how the people we call disabled have important roles to play in creating peaceful, fulfilling, sustainable community.

The people of the world who are called disabled have quiet voices. I will write my quiet words and express the silence of my compatriots. Perhaps I will discover a way for us to be appreciated for who we really are. Perhaps the quiet voice will move the world.

A Gift of Intimacy

Imagine that not walking, not talking, not seeing, not knowing how to cross the road -- all the many things we call disabilities -- were in fact a gift. Imagine that behind all this is a possibility unavailable to most human beings.

The following is a dialogue between myself and my friend, Gloria. One of my personal assistants, Sebastian, also speaks at several points.

Gloria is the mother of an eighteen year old son, Scott. Scott has never had eyes. Early in life he reacted badly to a vaccination and developed many vulnerabilities. His hearing is limited and his physical mobility is almost as restricted as mine. For many years he has had difficulty eating. He has been close to death many times.

At the same time Scott has many friends. His high school chums have musical sessions at his house every week, go with Scott to roller coasters and other wild adventures, and make presentations with him to elementary school classes about how great it is to have diversity in your circle of friends. His vibrant team of intevenors, (personal assistants who can interact with him using deaf/blind communication), are devoted to Scott. It is clear that Scott draws people in and reaches out to others through the fragility of his physical body and the brilliance of his spirit. People vie for a chance to sit with Scott in their lap because his presence moves, centres and uplifts them. Scott has a unique gift of intimacy.

Well, not quite unique. In my experience this gift of generating intimacy is often possessed by people who don't speak -- people who are considered to be nonverbal and, often, accused of "significant" cognitive impairments.

I spoke with Gloria about how "disability" is perceived by others and how that affects Scott and I. We talked about intimacy: The following is a transcription of our conversation.

Judith," That's how we're going to start the book right? -- I DON'T WANT TO WALK!!"

Gloria, "Really, your nuts, what's the matter with you? Why would you think that? You don't know what your missing."

Judith," Well maybe I don't. So, that's okay. You don't know what your missing either do you?

Gloria,"I can't be missing anything can I?

Judith,"It's the background idea that only you're aware of what's possible. Only the normal range of human ability is the acceptable range."

Gloria,"So that's how you want to start the book. I think it is a really powerful start. For me anyway."

Judith, "Gloria the dilemma of writing the book to me is that I really want this book to be about me and to be my book, but to be me and to be about me is to include a lot of other people, all the time. So you were asking me before about boundaries, and about intimacy. I think that the book is about exploring these. What is the boundary that defines you? And what's beyond your boundaries. I am not sure. It's pretty clear to me that you're not sure either."

Gloria, "Yes. I think your hitting on something here because it's what was most important to Dawn, (another parent of a teenager who doesn't speak), was that sense of the boundary that we have. For us it's usually our bodies. We're very clear and we're very violated and very vulnerable and very frightened when that boundary is violated. Even when I'm not violated but just intruded on by people coming too close. That concept from your perspective is really worth exploring."

Judith, "The other way to look at it is this -- what's available is intimacy. I think of intimacy as no clear boundary between you and me and you and him and me and him and so on. That is what it is actually. The absence of a clear boundary so that something about the interaction is going on between us and is generated by both or rather all of us and it doesn't belong to any of us specifically. So the meaning of my life is entirely that my life is my life but yet my life isn't possible without the active generation of it by several people at the same time all the time. There is almost never a point where you can say that I am clearly generating my life by myself. I don't know if there is really a clear time for anybody when they generate their own life by themselves -- but they have that illusion. And they carry around that illusion all of the time as if it was real."

Gloria, "And it's powerful. It's power for me. And power is an important word here because for me it's power and one of the lessons I learned with Scott is what real powerlessness is and that was always a struggle with bureaucracies or agencies or associations that they take away my power and I thought taking away my power would steal my life, my life force."

Judith, "You also said that you discovered that you can't support and save Scott by yourself."

Gloria, "Yes."

Judith, "That's when you really gave yourself up to power. When you realized you can't do it by yourself you became powerful."

Gloria, "Yes, I was stripped of all power before I became powerful."

Judith, "Yeah, well actually power is generated by intimacy and not by a singular human being."

Gloria, "The illusion that we talked about earlier. If you look at your Naturopath, who shall remain nameless, he is a really good example -- he is a good doctor of natural medicine. He has a brother who is in a coma and yet when he looked at you..."

Judith, "Not anymore."

Gloria, "Good, was it a coma?"

Judith, "Yes."

Gloria, "...he still saw you as somebody who he could make walk. That he could make that statement and want that is a preface to being his mother's son who wants to make it

all right and fix it all. He really wants to make you walk and that's pretty scary that he thinks that he can do that. And is it the failure of being able to make people walk again that makes doctors talk about the quality of life and finish people who don't walk off?"

Judith, "Oh I think so. My life is about living in the world where virtually my earliest memory is that I knew that people would rather kill me than have me go on living. That's one of the stories that I tell most people. When I was six years old I was sitting in the bathroom with my Dad who was helping me, getting me out of bed at that point. He told me that in his day they would kill kids like me. He told me that story because he had just heard in the newspaper or on the radio that they were killing kids with Down Syndrome in California. This was forty-five years ago."

For him that would have been twenty-five years back from then. It's been about seventy years since that story was generated. He was saying they would have killed kids like me because they didn't know how to sustain me in that kind of world where what they did was raise cows and potatoes and dig stones."

That's what they did, right? Somebody with Downs Syndrome could do that. So they didn't make a distinction. It's not that they didn't know the person was handicapped but that didn't matter to them."

Gloria, "They could do the work."

Judith, "I wasn't able to that so they would have killed me. So I've known always that I am likely to be executed. Simply because I couldn't walk and don't use my body in ways that people typically think. So that's really what my story is about."

Gloria, "At the seminar the other day a woman said that in Saskatchewan or Manitoba they had star charts -- they put stars on charts of people who were older or who had strokes or brain injuries and babies with disabilities and everybody knew what the red star meant."

Judith, "Let this person die."

Gloria, "Yeah, and she was in that facility, she worked in that facility and everybody knew what the star meant. Then seventeen years ago when her brother was born with a disability she saw the red star and she knew what they had done -- they put the same red star on the chart of her own brother which really brought it home to her because she hadn't really examined where she stood on the red star until she saw it on her brother's chart. I think where we went from there was that Latimer, in fact, Tracy Latimer's life put the debate in the open whereas before babies were always put in a room with the door closed and were allowed to go and starve to death or they were neglected to death."

"When Scott was at preschool there was a family from China, maybe the Philippines, sorry I can't remember, but the mother was terrified to leave her daughter at home -- she had Down Syndrome -- because she was constantly walking in on the father putting the pillow over her daughter's head. They had a son and a daughter and it was a fact of life in her household that she had to be diligent or he would smother her the first chance he got. And when Scott was born it was mentioned to me: "Don't worry, dear, if you're lucky he

will die." From the minute he was born it was clear he was an oddity and a specimen and lots of doctors wanted to write him up."

Judith, "Scott's supposed condition is?"

Gloria, "Fraser's Syndrome. Dr. Fraser found dozens and dozens of kids in the Appalachian mountains who were born without eyes. And they had a condition that was so referred to as Cyclop's Condition. So they actually had pictures in magazines in medical texts of kids with their ear canals formed outside of their skull. The ear canal stretched in a coil can come out to here. And eyes down here and one eye not two eyes. They showed me that - they were educating me so that I wouldn't have another pregnancy cause this is what it could be. I had nightmares about monkeys and monsters and about having another baby and all the doctors around. It was really clear, too, Judith that they would all be standing around going like this (rubbing her hands together) thinking: "Monkey or monster what will it be?" It was literally quite clear to me that their interest in him had nothing to do with him but it was about the oddity, the study, the specimen."

Judith, "So the other side of all this is that for me where I want to go with it is that Scott really is a person and Tracy really was a person."

Gloria, "and you..."

Judith, "And I really am a person. And what is that? We're raising a whole issue about quality of life, too. Like how to not only claim it, but to actually make it visible. I don't just mean that I am a person or that Scott is a person but I think that it really is invisible to most people that we are people and that we actually do operate in a world of power and actually do contribute already. What stands in our way is first of all this huge wall that people think we're dead or should be dead and then secondly there really isn't an environment that's working for us most of the time.

Gloria, "You've helped me on something. I go ballistic when people are parking in spots marked as handicapped sites. But you just talked about the environment."

Judith, "Most of the time my being in my little world would be like putting you on Mars and saying go ahead - make a life."

Gloria, "You wouldn't have to send me that far. it would be enough to give me a map to read to get through Toronto and I would be as lost and not capable of doing it."

Judith, "When your that... (and I don't want to use the word "disabled" because it means something else, right?), ...but the actual disability is that the environment doesn't work at that moment and you become a person who is essentially incompetent."

Gloria, "The environment doesn't work and that makes you disabled, of course."

Judith, "So there's a whole lot of incompetence that's placed on me or on Scott or on Tracy."

Gloria, "Your giving me language here. There's incompetence placed on Scott by the environment. Incompetence placed on you by the environment. You can live here for two years, Judith, and then you can have a ramp to get in the front door."

Judith, "So what will that mean to me for two years? It means that I will appear to be a person who doesn't really need to get out of my house. So when the time comes that I say I want a ramp on my house they'll say: "Why didn't you ask for that before?""

Gloria, " You would know no one!"

Judith, "The environmental obstacles create the appearance of my incompetence. "Why do you need to have the support you say you need because your incompetent?"

Gloria, " So the title of the first chapter of your book -- let's play around with that because of all that we've been talking about. What can the first chapter be titled? I DON'T WANT TO WALK"

Judith, "Could be. I don't know, I Don't Want To Walk? I don't want to sound like I refuse to walk. If all of a sudden I woke up one day and I was walking I would walk. I'm not refusing to walk by saying I don't want to walk. What I am saying is there is nothing in me that wants to go in that direction. It's not natural to my being. I can be who I want to be without walking. Walking doesn't show up for me as something that is missing in my life. There's lots of things that show up as missing but that's not one of them. And I don't think seeing shows up for Scott as missing. I don't think speaking shows up as missing. He will speak some but not much. Not much of his own volition."

Gloria, "Most of his needs are so well met by the universe and us that he seldom needs to speak. That's interesting about what you just said about walking. To me I see a real stepping stone in Scott's intervenors and their relationship with Scott. Somewhere after being with him for some period of time -- sometimes it's three months, sometimes it's a year -- there has to be some significant chunk of time -- they start dreaming about him walking and they come and they're so excited because they think it's a vision or they're so sad because it hasn't happened yet. And they're laughing and they're crying as they tell it to me and it never happened to me as his mother -- I never had that dream. But I'm not sure if there isn't a significant person in his life who hasn't had the dream."

Judith, "Almost everybody does the same for me, too -- the dreaming about me walking."

Gloria, "The dreaming, yeah, and the naturopath saying that."

Judith, "Most of the time when people dream that I am walking I think they're saying I accept you for who you are, and therefore I think you're like me. And walking is so important to you guys. For what reason I am not sure of. I'm not saying that condescendingly. I really don't know, right? I haven't had that experience. It is so critical to you that I think that's your way of responding to my situation. You try imagining me walking. So when the naturopath says to me if you did x, y or z I'm sure you can walk he's really saying he respects me, That's what he's saying. Other people could say the same thing and mean the opposite. They don't think I'm a potential centrefold."

Gloria, "'Cause you are the fixing unit. These people, they are attached with their bodies. I'm wondering about that intimacy issue. If it isn't when the barriers have completely fallen between them and Scott that they're able to do that. 'Cause it does connect with them feeling really enriched, really connected and in relationship with him."

Sebastian, "A lot of people their heart's are in the right place but what they're doing is actually destructive."

Gloria, "It can be if you let it mean that."

Sebastian, "I guess it's dependant upon how our value gets placed within that system of thought and interaction. It's not an easy thing. If you value walking then you see not walking as not valuable. If you see not walking as not valuable then you'll constantly be striving to create the conditions to help somebody walk who doesn't necessarily either want to walk or can't ever walk. Either, Or both. I'm just trying to follow along here."

Gloria, "And that's what's really important about what we're doing because we really don't know what it sounds like to be deaf and mute. We aren't living it or haven't lived it everyday and you did live it for a while and you have a good memory of losing abilities. When I go to speak at the university I won't understand how important what I am saying is and how it changes lives until they do a report and they write about what they learned. I read them as if I am hearing about somebody else talking about somebody else because it's the life I'm living and the life Scott's living. And that's the problem you'll face when your doing this book, too, because your living it."

Judith, "I think I'm hopeful that people will take more from who I am than just translating me into a walking person's language."

Gloria, "Oh that's perfect -- a walking person's language."

Judith, "All the time, everything I do, they translate into that."

Gloria, "A speaking person's language. I love that."

Judith, "I never hear myself... I rarely, rarely hear myself back as a fully accomplished human being who doesn't walk."

Gloria, "Really."

Judith, "Almost never."

Gloria, "You know when I look at you and your life and look at Scott I don't even see the disability or I don't see the disability first. I really don't. I don't even see you as having a disability because you can tell us what your thinking and feeling and expressing. And I know that you'll tell me that Scott does that too."

Judith, "Yeah."

Gloria, "It just feels like he's a little more vulnerable in doing it but I don't know if that's true. And there's more responsibility on us to listen for what he's saying and to listen carefully and for a long often time. But people that listen to you don't have to listen often and for a long time. But they do have to hear you -- and they don't hear you because you don't walk."

Judith, "That's because they translate it into walking person's words what that must be."

Gloria, "And they have so much emotion and history and conditioning that they don't see you."

Judith, "Take it one step -- a lot deeper -- 'cause I'm living in this world right now. I've lived in this world all my life."

Gloria, "How many years?"

Judith, "51. I was born into a planet of people who can walk. I'm only just in the last ten years, fifteen years, been able to figure out what I've adopted as being a walking person's language or a speaking person's language which isn't truly authentic."

Gloria, "Is not authentic?"

Judith, "Yeah, which I wouldn't have generated on my own if I had lived in a world where I was the norm."

Gloria, "The average end. It strikes me that when I came to Toronto for that activity, is it the Rosemount Hotel or whatever it is? I came to Toronto for the Summer Institute that year."

Judith, "The Primrose Hotel."

Gloria, "The Primrose. To see Black Americans wearing chains around their wrists. You should have seen it, Sebastian, they were wearing jewelry. It was beautiful, they were beautiful chains, right? But they were pieces of jewelry but they were clearly chains of slavery because after they got the chain around their wrist they then dangled so it was really clear that they'd been cut. And they were really clear about who they were. And the power in that was incredible. The expression of it -- the power of it. What really struck me is how many people would be offended by that and the courage it would take because they intended to offend. They intended to remember their history and intended to educate their brothers and sisters. And they intended to make us examine our conscience. And it was powerful."

Sebastian, "Your making me think we live in a world where experience creates a paradigm of knowledge and sometimes it is hard to break out of that paradigm of knowledge because of your experience. Whether that's socialization or whatever."

Gloria, "It occurs to me now we should say everything we just said now to the Portuguese man who lives two doors over and has the shoe repair shop."

Judith, "Yeah."

Gloria, "Because if we can say it to him, then he should be sitting here having wine with us, too. Because if we can say it to him then we can say it to anybody. And you know its not a bad idea that we do this on a regular basis and he comes over and..."

Judith, "He would come over."

Gloria, "And he would and he would say I understand."

Judith, "He would."

Gloria, "Yes and he would actually get it. He's suffered, he knows about suffering he knows about not being who you thought you were because other people don't believe that you, that who you think you are, is real. He's been through that stuff. The immigrant experience."

Judith, "I'm going after that and, I'm going after trying to discover people that I think I have something in common with. People like Scott. But even then I kind of like to sit between Scott and you in terms of what I would say -- where I would come from -- in terms of my own experience and ability."

Gloria, "And you do do that. You remember to be Scott when I don't remember to be Scott. You do it better than I do."

Judith, "Yeah, I'm wanting to because I think that he can teach me something about the fullness of my capacity. Because he's even more deeply lived the experience of being a person who has a different range of abilities than normal. And he also doesn't speak so I think that he -- I don't know, this is just a hypothesis -- he might have already figured out how he doesn't have to compare himself to people who walk. He might have, I don't know that."

Gloria, "Well I think about that, and I say to him, 'Scottie the puppy is doing this.', and think, 'Oh, Scottie can't do this.' and he laughs like, 'Oh, neat, the puppy's doing this.' And he thinks thats just great. Even though he can't do it."

Judith, "I think that Scott could show me a lot about the human condition. I want to learn from people I know or know now that they possibly had the opportunity not to compare themselves to people who are normates."

Gloria, "People who had the opportunity not to compare themselves with the norm -- people who think they're normal."

Judith, "Normates."

Gloria, "Alright this has got to be a book for the masses. 'Normates' is good. You can have terms in it and a glossary and an index."

Judith, "Because all of that is human experience 'cause we're all human. So all of it's experience. So some of us are getting the chance to have some very unusual intimate experiences. I think that my sense of intimacy is lightyears ahead of most people's. And still probably limited compared to Scott's I suspect, right? I think that in itself is worth it, right? My sense of how to deal with a hostile environment is very well developed compared to lots of other people. And my sense of getting something done in terms of getting other people to do it rather than me doing it. It also is much much different than many people experiencing getting something done. Do you know what I mean?"

Gloria, "Something I want to talk about just quickly before I forget. Tonight is something which gelled for me. I think that Sebastian likes to do one thing at a time, do it well, get it accomplished and do the next thing and that's a gift I wish I had. You also don't have that gift. Your mind is racing and my mind is racing and the time when I am most disabled, Judith, is actually when I'm sitting in a chair with Scott in my lap. I can't get up my knees won't do it cause I'm stuck. But I am also directing on Scott's behalf what needs to be done."

Judith, "Just like me."

Gloria, "Exactly, And I have a self-righteousness of doing it all on behalf of Scott. And there's got to be some of that with you. You – you're the employer, your the person with the disability, any kind of grace anybody's going to give you is going to wear off pretty quickly. But there is a moment where there is that grace and you put up with her because this is her. And you put up with her because she's your employer but I'm not talking about you I'm talking about Karen and Scott."

Sebastian, "Of course there are times when I feel like telling Judith where to go. Just like I'm sure there's times where she grants grace upon me and doesn't tell me where to go and stuff it."

Gloria, "And Karen, Karens's really great -- she works so hard for Scott. When I'm directing her she works twice as hard because it's the employer, somebody she respects. What it brings to mind to me is how fast my mind is working because I've done it a thousand times and I know all that I needed to do and I don't want steps left out. And you must be like that because you talk about all the steps, you know 300 steps to get you out of the bed in the morning and if one of them is missed its uncomfortable and physically could even hurt you. And how difficult it is, what it reminds me is how slowly you must be living your life compared to how quickly your mind is ready to live your life. And I think the same of Scott. I think Scott is just infinitely patient with us. And I think of Caroline, Caroline is just a big grin and knowing eventually we would figure it out and being proud of us and we figured it out. Sort of like Sebastian knowing that you just now wanted red wine. But your living faster than anybody can support you I think is what I am talking about here and what does that, how does that feel?"

Judith, "This is a good analogy. What I know is he hasn't got it yet. 'Cause when he gets it – it's okay cause he just started, right? When Sebastian gets it I can tell him everything I want and he knows I don't expect it all at the same time. He'll do it in the order that works for him and if I need some piece of that sooner I'll say so and none of it will be pressure. 'Cause that's how your mind works when it's telling your body, right? You have

a vision of supper. We're not going to do all of those things at the same time, right? In fact it's about an hour and a half."

Gloria, "That's very important. I need to help Karen see that too."

Judith, "I just set it up so that he sees what I'm seeing. We're not going to do it all at the same time. We're not going to do some of it until tomorrow..."

Gloria, "Karen's off and not back until Monday. I have to tell you that when Karen's not doing all the things I think she should be doing all she needs to do is have a weekend away and suddenly I'm appreciating her like hell. Because when you got somebody who's really able to move throughout.... The reason I get frustrated is because she's been perfect and the priorities change in her mind and you know that she was right. It became that Scott wasn't doing so well and he was home everyday and she didn't have that one or two hours in the house without Scott to do all the things that I had expected her to do. And I had some time with Scott on the weekend, quite a bit of time, and several mornings and six hours each morning and I loved it -- I loved being with Scott. But it was like wow you can do this or you can do that because you sure as hell can't do them both and I'm really glad that Scott chose to do that. Karen chose to do that."

Judith, "Almost because of Scott."

Gloria, "Yeah, I think it was Scott. Scott didn't tell Karen to get the damn laundry done. Scott said come here and look after me and help me be with my dog and my cat and my mother and with my friends."

Judith, "Probably Karen actually does read Scott better than most people would."

Gloria, "I agree. There is genuine relationship and she is being fed very richly from it. And she, you know what else is that she knows it -- that's the surprising bit for me -- is that she knows it because I see lots of people who are just hungering for something in their lives who get it from Scott and don't know they got it from Scott. I think that's where we talk about the stealing contingency. But she knows it. She is very clear of where it comes from."

Judith, "People steal that a lot."

Sebastian, "I think about the connections between intimacy and relationship and communication because every contact is an intimate contact and that comes through communication and how everybody has different types of communication. And I was thinking earlier when I was thinking about paradigms it left my mind but how I used to think that language was power but now I'm starting to reform that thought and it's communication that's power because that's the basis for intimacy and contact."

Gloria, "Yes. Judith there's some more of that really nice wine would you like some of that?"

Judith, "So the book is to me some way of really making it visible that I'm here and that being here is a different experience perhaps but not a lot different. But just how different is it?"

Gloria, "It's measure is how your going to define "different". And do you get to do that or do I get to do that?"

Judith, "I'm not supposed to do that -- that's the reader's job."

Gloria, "The reader gets to do it. So we need touchstones. How would I feel about that?"

Judith, "What from?"

Gloria, "That in your book, that -- about personal intimacy space, personal care, marriage, divorce, brushing your teeth. I have to tell you in my mind there's no doubt that there was intimacy in sex and in marriage."

Judith, "Yeah. Before and after too."

Gloria, "Good, good -- glad to hear it. I remember being really happy watching you brush your teeth 'cause I was clear that there was all kinds of possibilities in terms of sexual intimacy. And for me that was WOW!!!!!! look at that she can do it! I don't need to know the details but the book will want the details, Judith. But it was -- it made me happy. There was no pity in it. It was, "Oh yeah!" -- sort of like the Oprah Winfry show. You should start watching her if your going to go and see her. Oprah Winfry saying, "You go girl!" -- you know. That would be my dream that you would be on Oprah Winfry and that topic would come up and she would say, "You go girl!" But you know that it is just as likely that someone would say more information than I wanted to know. But every single person would flip to that chapter and read. I don't know how many paragraphs you would give to it."

Judith, "Maybe the point is though that that was what connected me to where you feel something that is important about yourself."

Gloria, "I don't want to look at that at all so just keep moving on this. Alright lets see."

Judith, "Well for somebody else it might be something else. For you, you can imagine being me if I can have a sexual relationship."

Gloria, "I was happy for you and happy for me that you could have sex."

Judith, "So thats's what you figured -- then it was okay, right?"

Gloria, "Yes absolutely. And I would bet that that is a touchstone for most people. First of all the curiosity. But I think that we've found one of the touchstones for the book."

Judith, "What are some others?"

Gloria, "That you don't want to walk is a touchstone."

Judith, "And, I think, what are some other ways that people get that it's okay to be me? For you it's what we talked about. Now, for another person its..."

Gloria, "And I was blown away that you weren't doing art. I mean because everybody who is like you does paintings with those mouth brushes."

Judith, "Oh my God I hate that."

Gloria, "Let's talk about that. There's a touchstone there. "If she can do that with a toothbrush it probably means she had a great sex life. Why isn't she painting something?" Well one of the things they said to me was Scott really could go to W Ross MacDonald. At five years old he could leave home, come home occasionally. But you know what? They have an olympic size pool and he'd learn to play the piano. And there you go – that knocked out everything we could have given him as a family."

Judith, "It certainly is better than being with your own family."

Gloria, "Being a son or a daughter or being a brother or sister. I think that touchstones is an important word. What does touchstone actually mean?"

Judith, "I think it's like when somebody is in a race and they touch a certain point and that's the anchor point that they've actually done that part of the race."

Gloria, "Alright I think."

Judith, "For some people it might be things like if I can pay my mortgage it is a touchstone."

Gloria, "Yes. There's something in the word "touchstone" that's pretty... Speaking of touchstones, I sat with Bobby Stevenson today and I forgot... She was saying that her daughter is living out of her other daughter's apartment. So they're looking for a roommate for her daughter who has a disability and I'm being more clear because somebody who is going to listen to this and needs to know some of the background. She was really feeling challenged by it. We were whispering and I said you know we had people who were dying to live with Scott. They were so happy to be living with Scott that we couldn't get them out of our house. And we moved to the cottage for six months and we had to arrange to have our house painted and we said they had to go because we were painting and moving back. But they said where will we go? What about us? Because they were so committed to being there living with Scott. And she said after, "Thank you for shifting my perspective. It is a paradigm shift. It never occurred to me that people would want to live with Scott." It's completely changed how she's looking at a roommate. And I talked about Kara Balmer who is blind and deaf and her family have her living at an apartment with three university students and the thing is they found that three works and they don't burn out. They need to learn deaf blind sign language. One is always willing to stay behind because they're tired or have a free period or they got homework to do. So at night there is always somebody who can stay over night. It's one of the legal requirements of the agreement that there is always somebody overnight. And the other thing they discuss really clearly is you have four roommates and your building friendships and if

three roommates go off to the pub the fourth roommate should go. And that is the reason you become friends. So without identifying relationship and intimacy her family got really close to the issue which is that you don't become staff and then go off by yourselves."

Judith, "Touchstones."

Gloria, "You know that's your title -- Paying The Mortgage."

Judith, "One of the things I think we can say that's true about people who don't walk and don't speak is that it makes sense to them and not only does it make sense to them but they actively generate and actively develop skills around intimacy."

(to be continued)

*Sign Tony
Key Christian
Story in desert*