



Interviewee: **Catherine Dopp**

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Interviewers: **Athena Aardweg, Judy Barricella**
& Tony Buba

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Judy: Catherine, if you could just state your name and where you were born or where you live and a little bit about your family. If you have sisters, brothers, mother, father...

Catherine: I have nine.

Judy: Oh. Well, you don't have to tell us all the names!

Catherine: There's nine kids. Okay.

Judy: So go ahead. Tell us your name and where you were born, where you live and...

Catherine: Okay. My name is Catherine Dopp and I was born here in Pittsburgh at St. Francis Medical Center. And my father was a welder for Drove Corporation and my mother stayed at home all day. They had nine children. I'm the youngest. And that's probably why my mom stayed home. And her name is Catherine and I'm named after her and my grandmother, so that's like a special name to me. And I grew up in, it's called Brighton Heights. It was part of North Side. We wanted to distinguish that. We were not lower North Side because that's where drugs and things like that happen. And I grew up there and went to Catholic grade school. And we walked home for lunch. We walked back and forth. We didn't pick up, no cars coming like I go now. So different. Then I went to Catholic high school, graduated. And then I went to community college and I have an associate's degree. And then I went to nursing school, St. Francis Medical Center. And I'm an RN. I graduated in 1986 and I was only able to work for approximately three years, and I think that fourth year I just took off. And then I just became so disabled with my disease, multiple sclerosis. And I have a whole line of other problems.

Judy: Where you diagnosed with MS before that time, or...

Catherine: I was...right when I got out of nursing school, at the end we had a neuro. And we...and she was saying, and I'm like, oh that's me. But I didn't have time to think about it. I don't want...you know hey I have my boards and graduation, things like that. And now everything comes into play that I did go to the doctor's. And I had it since I'm sixteen, but they go by the age when they got it diagnosed and that's was when I was 23.

Judy: Well, how did they know you had it since 16?

Catherine: Because that's when all my symptoms were.

Judy: Oh, they went back.

Catherine: Yeah, we went back. But that doesn't count. Only when we diagnosis it. And that's a pretty young age to be diagnosed and a...then I...I lost my train of thought.

Judy: That's all right. You a...

Catherine: I was diagnosed with the disease and after that I couldn't work too much longer. It was the fatigue that got to me, and then I went into a flare up. And back in the 80s they did not know how to treat MS. So they...I wasn't treated correctly with medications and things like that. Now it's a whole different story. So...and then I've lived through a brain tumor. I had a brain tumor. I did get...live for that...I came through it. And a...

Judy: Was it surgically removed?

Catherine: Yes. It was pituitary adenoma. And I had that. And I've been in the hospital so many times. If it's not for my MS, my flare ups, then I'm there for metabolic reasons or, I had kidney failure the one time. I was...so, I kind of know what hospitals are like.

Judy: Do they think that these things are related to the MS at all? Or not?

Catherine: No, everything's all distinct.

Judy: Mm. Aren't you lucky.

Catherine: Yeah. Everything's all not related. And I went...I had to go to a nursing home. And I lived there for 22 months. And here I am. And at the time I wasn't able to do anything, but slowly I came around. And I saw my walker over there on the...by the wall. I said, okay, I'll make a deal. Which I know Jesus we don't make deals. But we'll make a deal. I said I didn't know how fortunate, how lucky, how blessed I was to walk with a walker. I want to walk. So I said I won't ever complain, about it. This is my best friend. And guess what? It is my best friend. And I'm walking.

Judy: Good.

Catherine: So that's just...and my doctor he's just like you are my poster child for this drug. It's a chemo drug. And the chemo I have a limited time to stay on it because of the side effects of what happens...damages the liver and the heart. So I can only...

Judy: What are you taking?

Catherine: Novatron.

Judy: Okay.

Catherine: So I'm still on it that and a...

Judy: So how long are you allowed to stay on it?

Catherine: It...they keep blood work with your liver and your heart and they do a left ventricular wall motion test to see how the heart is pumping. And a...mine's getting a little shaky and he's a little nervous. But I'm like quality. I just want quality, not quantity, quality. I just want to stay where I am now. Or even get better. Which that's possible. But anything's possible with Jesus.

Judy: So you...

Catherine: I'm Roman Catholic by the way.

Judy: Okay. You said you went to Catholic school.

Catherine: Oh yeah.

Judy: Grade school, high school.

Catherine: Yeah.

Judy: What high school did you go to?

Catherine: I went to Holy Ghost High School. They closed. They lied to us. Then I went to Mount Alvernia.

Judy: Did you?

Catherine: Oh, and I hated Mount Alvernia.

Judy: I went to Mount Alvernia.

Catherine: I hated that place.

Judy: But I went a long time before you did.

Catherine: That makes me feel good. Feels like I'm young.

Judy: May I ask you...

Catherine: Not that you're old.

Judy: No, I am old. Can I ask you how old you are?

Catherine: Why do you need that?

Judy: I don't need it. I'm just curious. I just was sort of trying to figure out how long it's been since you had MS.

Catherine: I was diagnosed when I was 23. And my birthday is this month, May 22. I was born in 1964.

Judy: Oh, that's the year I graduated from Mount Alvernia.

Catherine: So, that makes me that, I believe, I'm turning 44.

Judy: Oh.

Catherine: But I just love when people say you look much younger.

Judy: You do.

Catherine: Oh, thank you.

Judy: But 44 is young.

Catherine: Not to me.

Judy: She's been working with MS for 20 years.

Catherine: Yeah. And I've been pretty incredible with all the things I've gone through.

Judy: You ended up in a nursing home for rehab or just because you couldn't take care of yourself?

Catherine: My mother was just too tired out. And she's an older woman, as I said how old she was. And she just said, Cath, would you do this for me? And I always...she has done everything for me, and I said I'll do it for you. But I never knew how...It was very...I was depressed for at least 9 months. It was very hard. They wouldn't let me go out and I was in that nursing home constantly.

Judy: Where were you? What nursing home?

Catherine: I was at Ross Kane.

Judy: Oh you were at Kane of all the places too?

Catherine: Yeah. And it's really sad about how so many things happen that people don't know. And they say, oh you're fine there, you're good there. Look how much

you're...and there's so many things behind the scenes. And how some nurse's aides don't like you. So they'll, tough. You know.

Judy: Ignore you.

Catherine: Yeah. Then how do you get help? And then when you do, you know, how there's a lot things that go on. I came out in 2002, May 31. Because that day is when my father went in the hospital.

Judy: The day you came out of Kane?

Catherine: Yeah. He went into the hospital.

Judy: Oh.

Catherine: He has pulmonary hypertension. And he almost died so we went through all of that. Then the next year it was my mother's turn to try to die on us. And thanks for...and then you know she's gone in many times, and thank God I became an RN, because I know what's going on, and I saved her life and she had to go to rehab for nursing homes. And they don't like to do things and I'd go out and like my mother has, you know, upper respiratory infection. They're like, "She just has a cold. It's nothing." I said, "Yeah it is something. I know." And I said, "I can here the rattles and different things." I said, "I want a chest x-ray." "Well we can't do that." I'm like... I said, "She probably has pneumonia." And they wouldn't do it. I said, "You call the doctor now and you get the order." And they called the doctor. They got the order. And she had pneumonia. And they put her on breathing treatments and she did come out of that. But, I mean, there's been antibiotics they put up. I'm like, "She's allergic to that." So, I've been in the right place at the right time.

Judy: So your mom's still alive?

Catherine: Yeah.

Judy: Your dad.

Catherine: Yeah. Everyone's like they are so sweet. Oh are they cute. And now I guess because they've lived how many years. It's going to be 65 this year. That they just kind of like, oh he doesn't do this. Like, oh don't listen to her. I'm just like...they're like two com...it's a comic thing to see. And it's nice to see that they're not mean to each other. You know. Joking.

Judy: So you live with them?

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Catherine: No, I live independently. TRCIL. Three Rivers for Independent Living. They help me out. And I live at Avalon now, in a HUD building. And that was stressful and it's still sometimes stressful when you have people coming in helping you. It's stressful because some of them take advantage of the person. They do...their fingers seem to want to walk to things that are expensive or something priceless. And that's what's hard.

Judy: So you've had those kind of experiences?

Catherine: Yes. I've had \$250 stolen off of me. Now I have a \$650 bracelet. And I'm like...And I just can't be there babysitting constantly. Because that's what I do. I baby-sit them. And it seems like everyone thinks it's their home, not my home. It's my home and I like to do things my way. And I know I'm a picky person, but...

Judy: So you've had to fire some folks?

Catherine: Oh yeah. Oh yeah, lots. And TRCIL weren't...at that time they weren't too pulled together. And it was pretty sad what happened that I wasn't getting care at all. People were not coming in and... The one weekend I only had four hours. And here I am to get 38 hours. So they did their laundry that week, but, yeah it was really bad. I'll admit that, but now, TRCIL has really turned around with individuals here. They've really turned it around and making it better. And I've seen a difference.

Judy: Good.

Catherine: And now I'm volunteering here.

Judy: Oh.

Catherine: Which I said "Forget it. I'll never go in that building. I will never go. Never." After was...and now, here I am.

Tony: Now for reference to the tape everybody knows what TRCIL is but could you say what it means, TRCIL?

Catherine: Oh yeah. TRCIL is Three Rivers Center for Independent Living. And that's the state likes to give them the money to keep me out a nursing home because I'm more expensive in there than I am out here. And it's great to have independence. And it gives me so much freedom. And I go...Can I tell you that I go skiing. Snow skiing and water skiing.

Judy: Oh yeah. Is it fun?

Catherine: Oh yeah. And when I go snow skiing I just love it because I feel so free. It's just anything that makes me feel free and that's what I like. And when I went up hot air ballooning it made me feel so free. And then I went with dolphins...I swam with them in Key Largo

Judy: Did you?

Catherine: Five days. I have that on tape. And that just...oh they're wonderful animals. Wonderful.

Judy: So you have doing things with the Hope Network then? The skiing?

Catherine: Oh. That was TRAS, Three Rivers for Assisted Living...I me Assisted Sports.

Judy: Sports. Right.

Catherine: Assisted Sports, yeah.

Judy: Right.

Catherine: Yeah. So I've been going with them for about three years now. Last summer was the first I went water skiing. And that wasn't...It really pounds the body.

Judy: Yeah.

Catherine: Or snow skiing. It's...I'm now getting eloquent. And there actually...I'm really starting to come around with that. So...

Judy: Are you being tethered or not?

Catherine: I'm being tethered. And then if they're not comfortable and they don't know how far and if I wipe out, I'm like, oh. And the first time I wiped out I loved it. I like oh I wiped out. I can tell people I wiped out. Look I'm in the snow. I thought that was...I liked it.

Judy: Yeah.

Catherine: Thank...but thank God I didn't...never get hurt.

Judy: Yeah. Yeah. So you live alone?

Catherine: Yes.

Judy: And your aides come in once in a while or whatever?

Catherine: They come in for 8 hours a day.

Judy: 8 hours a day. And you're home at night by yourself then?

Catherine: Yeah.

Judy: Okay.

Catherine: There's been some problems every one in a while, but...you get through them.

Judy: You live in an apartment building though, right?

Catherine: Yeah.

Judy: Is there an onsite manager?

Catherine: Yeah. And there's a lot of problems with that on sight manager. And she's no longer working there. And a...she did not know how to work with the elderly. How she did so many things and how many times I had to call HUD and Fair Housing to say. You know, "Is she allowed to do this? Is this covered? Is it..." And guess what, I always won. I won. All the little things.

Judy: Yeah, you should be the manager.

Catherine: Well, I think that's why TRCIL likes me because I'm...I have been such a great advocate for myself. And I...And was very hard. That woman was not making my life easy. I mean she just...taking things away. I'm like, excuse me. I wasn't allowed to wash. She only...I could only do it at this time because there was some problem with...There's a little argument. I'm like...so, yeah, she took that away and she...She harassed me. She threatened me. She wouldn't... She said "I'm not letting anybody in. I'm going to board up the doors and I'm going to put chain locks on." And I'm like, oh brother. So she's gone. Just this...

Judy: So are you one of the youngest people in the building?

Catherine: No.

Judy: Or do you have a young person?

Catherine: Oh no. Two is for the disabled people and I just spoke about that, that I don't think that's nice to just...Because they always...Most of the elderly, since they are old from their age, they say invalids.

Judy: Oh.

Catherine: But I understand, because of when they were born and what happened. And...but they go that's the invalid floor. Oh yeah, that's where those people go. Those disabled people.

Judy: They put them all on one floor?

Catherine: Yes. And I'm trying to change that.

Judy: HUD. I don't think HUD.

Catherine: HUD...

Judy: How old is this building?

Catherine: 25 years old, so...

Judy: I don't think HUD allows that.

Catherine: Well they called HUD just recently and they are doing it because it was set up like that for the safety of all who are disabled. But what I brought up to them is, I would feel comfortable being where ever, and I had... the right was taken away from me to pick where ever...what floor I wanted or anything like that. And I would never been on two. I would've been up high because I like it. But a...Now I said, I've spoken up and I said, well there are disabled people on the list and they don't have to be on two. You can pick a... "Okay, we'll integrate them just hold on." So that's what I'm working on, to integrate us.

Judy: Do you have wheelchair accessible apartment?

Catherine: No.

Judy: No?

Catherine: No.

Judy: So where do wheelchairs...

Catherine: I mean if they are wheelchair accessible but not in our date of 2008. You know, this is way back. So, I have a cutout at my sink if I'm in my wheelchair, but I'm up and down and I don't...

Judy: What about in your bathroom? Is it big enough for you wheelchair?

Catherine: Yeah. That just happened by accident. It's not as if they did that on purpose.

Judy: Oh okay.

Catherine: Because all of them have it. Every floor has a big bathroom. So that it wasn't thinking for the disabled person.

Judy: So do they have specific apartments in the building that are identified as handicapped accessible?

Catherine: Yep. On two. Every one on two. The second floor.

Judy: Yeah. But that's not what I mean. I mean like that they... they have bigger bathrooms, grab bars...

Catherine: They do have...

Judy: Lower clothes rod in the closets?

Catherine: Yes. No, lower rods in the closet. They do have more things in the bathroom for us to...more bars. But...

Athena: What's different in those rooms that makes the second floor Quote-unquote "accessible" compared to the others?

Catherine: They said because there's a cut out at the kitchen that a wheelchair can go up to it. Oh, well I'll...I actually had them change my...the sink. And two sinks, their handles. They adapt that for people. But I asked them to give me the normal ones, because I didn't like those.

Tony: Now this is just strictly because of the audio recording. The answers are like short. Could you like take us through, you're getting off the elevator, help us visualize what it is going into your apartment and what you think, you know, how it is and you think it should be and what you do. Okay?

Catherine: Okay. I can do that.

Judy: Go ahead.

Catherine: Okay. What's nice though that I live on 2 is the elevator kind of just comes to 2, and it's always there for us. So, I know I'm going to get the elevator quickly. Get off the elevator and I go in and the door's pretty big. And I have to just push it open and, yes, the door is kind of, at the bottom, marred from my wheelchair. You know, in my electric wheelchair. And you're trying to keep that door open and you're trying to get your wheelchair in, so. Then I go in and they have a light on right there that I can turn on. And as I go in a little bit more I have the kitchen to the right, which is a pretty big kitchen. And they now just gave us...They just gave us new lights in our kitchen. There were so...It was so sad. I mean, you could not see that well. Now they're very bright. So, they said...In the kitchen the floor has been there for like, 25 years and looks dirty, but it's not really. I mean, I clean. We clean it, but it looks filthy and I just...it's kind of dim and kind of depressing.

And then I go in...I don't have a lot of room. I lived on my own in an apartment at my parent's and when I moved all of that into this it's...And it's hard with a wheelchair, getting around. I have an electric wheelchair and you have to keep everything out of your way. You don't want to...And I don't have any rugs in case when I do walk I don't trip. Sometimes the electric wheelchair for some reason can just get it caught up and I don't like that. And then once I'm in I...There's a light over my dining room table which is hard to get to. It's against the wall, but I have to...It's hard to put on and off. It's a distance and I...That gives us the most light though. And that's why I put it on. I don't like it though, but it's hard for me to get to and do that. And then I go and there's my living room. I like that I have a window and I have a beautiful tree, a bush. I see it all the different seasons and in the winter. It's so pretty when it, ice and snow on it. And then I go in my bedroom and supposedly when I go in, I'm to put my light on, but I can't have that because I only have one telephone...what are they, telephone jacks.

Judy: Jacks. Yeah.

Catherine: And so that's where my phone is and that's where I have response I have...where my...

Judy: LifeCall or something?

Catherine: Yeah, LifeCall. And thank God that has helped me a lot. But everything's in there, but guess where I do all the falls? My falls are all out in the living room, or in the doorway. So...Which I just put in now, and I'm asking for another jack to be put in. And I just got new life line equipment. And she said, "No, it really should be in the living room." And I said, "I fall out here in the kitchen." I'm screaming and I don't always have that voice.

Judy: But don't you have something that you press? That you hang around you neck or something?

Catherine: Oh yeah. Oh yeah. I press that but they're talking to you. Talking to me and I'm screaming.

Judy: Well, they should know if you're not answering.

Catherine: Oh yeah. But it's reassuring to hear voices. It really is reassuring. And a...Then I go into the bathroom and the bathroom is big. So... The wheelchair, if you have the newer ones, can spin on a dime, so I can go around, but, yes, many of us who are in our wheelchairs can't get through the doors. You have to take the doors off. I was lucky. My doors, if you saw them, I really right...I shred them. Right where my...And they're like well. I said that's...I can't help it, it's not big enough. And I jam it. I don't...It's just something there. So that should have changed. And my bathroom is like that, too. And it would be nice if the bathrooms were...had some warmth...The air conditioning comes on for us. I mean, I put the air conditioning or the heat on, but it's such an old place that it gets too cold or it gets too hot. And I'm just am fussing with that all the time. And with my MS I have a problem because my monitor doesn't work correctly. So...

Tony: Thank you

Catherine: Was that okay?

Tony: Yeah. Because it was just sort of fragmented. We're trying to get feel for the apartment. So this is an older building. 25...

Catherine: 25 years. 26.

Tony: So advancements in chairs that they've made over the last...and the apartments haven't kept up with those?

Catherine: Right. And now they... I'm getting a new chair, and I couldn't believe it, but it's going to be smaller that I'll have no problem getting through the doorways. But that's because they're making it smaller, it's not because they went to widen them for us. So...

Judy: What kind of chair you getting?

Catherine: I don't know. I had a Jazzy 113. So, I'm getting one of those, I guess. I'll see, I'm going to CAT at Pitt University. I'm going to CAT and I'm getting a new one.

Judy: The Center for Assistive Technology.

Catherine: Technology. Yes. The Center for Assistive Technology. And they are, they're dynamite. They are excellent, and...

Judy: Who do you see there? Do you know?

Catherine: I don't know the doctor. They always have a different doctor. So I couldn't tell you. And I do know the one physical therapist, but now that you're asking...

Judy: You can't remember?

Catherine: I can't. But I always have Able Mobility come and they're the ones who give me my wheelchairs.

Judy: Able Mobility? Where are they located?

Catherine: I'm not sure what area you call it, but they're right by the airport. Pittsburgh Airport. Right by it. And I had them...they were giving me scooters a long time ago so I could get around in my neighborhood or things like that. And um...Because with MS a person usually wears out, gets tired. And we used electric wheelchair for just a...give us energy later, to conserve energy. And I was out...I had no wheelchair for two days. And this was just a week ago. And I can not believe how dependent I am on that electric wheelchair. Because when I was doing everything myself I was up and down because I would forget something. And go back in and come back out. I was tired in my legs and my MS wasn't doing as great. So now I'm like, "Oh wow I do need that electric wheelchair." And a...I take the electric wheelchair and keep it at the highest speed almost. I know. I go to Ross Park Mall and I know a lot of people look. Another person asked how I could handle people staring. I said, "You know in the beginning when people stare you go into a restaurant or shopping." I said, "It hurts kind of." And it's hard but now I go in and I don't notice it anymore. I just go on my way and I just have fun shopping. Who really likes the electric wheelchairs are all the little children. They just look at it and they're like, "Wow, what is this?" And they're in their little buggies. And they're like, well that moves faster than I'm moving. And they see a little bit more lights and noises and things. So I talk to them and... Which is... Sometimes I used to be I didn't like that with the kids. I'm like, oh my, they're only 2 or 3 or 4 so I'm like actually seeing this they will get used to having people who are disabled out there. And be accepted. So it is a good thing that I'm out there. Because I have a nephew who is disabled. He has a shorter arm and he has problems. But the kids, and I can't believe how mean kids can be with disabilities. And I go to church and my church, to go in was a step. And my grandmother passed, so we were trying to get my manual wheelchair over that step to get in. It was very hard to do. But we did it. I was in there and things like that. So, I'm the one who said "Well it's only a step so could someone put some cement there so there will be a slope." And that's so much easier to go in. And I did that. It took me three years.

Judy: Oh wow. Three years.

Catherine: Three years and I said, he goes, "Don't say that to me again," you know. No, I kept on it and they do have it now and they have disability parking now. And the man who I was always talking to, his name is Bill, he has now come up with... He has a disease now, it's Parkinson's disease and he's using the walker. And guess what?

Judy: He uses that parking spot.

Catherine: Yep. And he uses that little slant. And I... They're good friends and I said, you know Bill did you ever think that you would be using what I was asking for three years and how it's helped so many people.

Judy: What church is that?

Catherine: St. Cyril's of Alexandria. Brighton Road.

Judy: Brighton Road? Oh, so you...I'm not quite sure I know...I know where Avalon is but I never could figure out how...

Catherine: Oh, this is in Brighton Heights, St. Cyril's.

Judy: Right. I know. I know. My cousin got married there. But Avalon...

Catherine: Is 2 miles.

Judy: ...is not that far from there?

Catherine: 2 miles.

Judy: 2 miles. Really.

Catherine: Yeah.

Judy: Okay.

Catherine: Because when I was a child Belleview and then Avalon because we would...my sisters would say come with me to Belleview and we would do shopping and things. But it's come down a lot now. It's not as oriented to, you know, stores.

Judy: So, your parents still live in Brighton Heights?

Catherine: No. My parents now live at Ross Park Retirement. Ross Park Retirement on Ross Park drive. It's...you look over and you can see Ross Park Mall really well. My favorite place.

Judy: Is it those gray buildings? No.

Catherine: A...I think they're bluish. Yeah.

0:32:00

They are gray-blue. It was just built and they have a lot of problems there with things. They...

Judy: Oh really?

Catherine: Well, some things are cheap. And this one man has no heat in the winter. I'm like, ahh. They did a shoddy job fast.

Judy: Who built it?

Catherine: I don't know. I'm not sure. Because they were trying to get information from the people who live there now. What's wrong? What could we make better? And there's a nice list. And what's bad about that apartment is when you go to my apartment when you want to come in, you would dial 0-0-4 for me. Okay. I get buzzed and I have to go to the telephone and push 9. And before I do that I can look on my television and see who this person is. That's really good...Safety. Now at this...where my parents live this is ran by Allegheny County. Mine is federal...state.

Judy: Your building?

Catherine: My building. But hers is Allegheny County. And now when someone wants to come, we can call and we ask them. They have to come downstairs and open the door for us. And these people are older and...

Judy: That can take like 20 minutes.

Catherine: I mean.

Judy: That's crazy.

Catherine: It's terrible. And they do complain about it and I don't blame them. And there are people who are in wheelchairs there. And there's people...

Judy: So, it's a wheelchair accessible right?

Catherine: Yes it is. But it would be really nice... I just feel bad because it's hard for my mom and dad because they're elderly now and they have problems with their lung and heart, as others. And you can just see them coming down and it's sometimes a big effort.

Judy: It's called Ross Park Retirement?

Catherine: Mm hmm.

Judy: I'm trying to picture where it is. Is it near Bob Evans?

Catherine: No. Up more. The McDonalds is... This one McDonalds is right there and go down and go opposite of that.

Judy: Oh. Okay.

Catherine: Toyota's back there.

Judy: Okay. Okay.

Catherine: Chinese restaurant's back there.

Judy: I know where you mean.

Catherine: Nelson's Road.

Judy: Yes. I got you.

Catherine: So here's a new building just built and they knew how many inches to keep everything for... you know, 36 inches, for, I believe, the doorway and you know what? They still... not that... It's not safe, accessible.

Judy: So what's the real name of your building you live in?

Catherine: Mine's Med Towers. Now that you s...

Judy: I know exactly where you live.

Catherine: Okay. Now that you said that everyone who comes you tell them the address. Well there's no address, no numbers. So I'm like, look, it says Med Towers. Because they don't... everyone looks for that address.

Judy: I think that building's older than 25 years.

Catherine: Well, it's probably 27 now. 27. But um...they have new people and they have a new board and they are making changes. And we're going to get new bathrooms and new kitchens. I asked to go to be put on another floor because the sink is low, and I'm 5'10". I'm a tall woman and I can't sit in a wheelchair and do that. I mean I just get all wet and actually I like to stand and I can do that and I'm able to do that. So I asked them to put me into a normal apartment. And then guess what? They decided no. They decided to come in and now they're going to put up the sink for me. At what height I want. So they'll do anything I want right now. And they'll redo it. So, like I'm going to have a phone jack put in. And now I have more of a chance of getting that jack because of my call. Emergency call. And she goes, "Oh I'll back you up on that." And I've fallen trying to get to the telephone in the bedroom when I'm out in the kitchen. And most people hear a telephone ring and they want to rush. Because everyone's pretty impatient.

Judy: Mm hmm. Mm hmm. Mm hmm.

Catherine: And I do have a tape recorder, answering machine, but you know what? Then he says, oh this is doctor so and so. And you're like...And then you put up...pick up the receiver, makes all that noise and...

Judy: Mm hmm. Mm hmm.

Catherine: So...And I have fallen many times. And everyone's like...But I'm like I have doctors calling me. So I'm paying a lot of money for my internet because I need that phone available. Because that's so... and I have many doctors. I have at least 6.

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Judy: Really?

Catherine: Yeah. So...all different.

Judy: For all the different ailments?

Catherine: Yeah. Oh yeah.

Judy: Just one MS doctor, though?

Catherine: I have Doctor Rock Hyman and he's at Pitt and he's just the best. And he is known to be one of the best and most renowned. And he's the one who gave me the chemo. He took that chance with me. And I do have Dr. Hasory is at...oh he's at Pasavant now. And I've been with him and he does the other things.

Judy: Okay.

Catherine: Because Dr. Broman is so much into the new drugs and getting those administered and really diagnosing MS very well. And Hasory, he'sI think he's been a doctor for like 30 years, 35. So, and I've been with him and he'll be retiring. But he's the one who puts me in if I need some rehab or if I'm having a small flare up. And he listens to me by giving...I'm like "Please don't give me big doses of the steroids." I want a lower dose. And a...he gives it to me because I don't understand but she says it works, so it works. That's what she does.

Judy: So how...so you feel you've been handling this MS pretty well?

Catherine: Oh yes.

Judy: Yes.

Catherine: Very well, I think. I'm a fighter.

Judy: Good.

Catherine: I'm just such...I'm a strong-headed individual was said to me by Med Towers because I wrote a letter saying all the things and they're like...And I'm always the one to speak up. And I speak up for the others, too. And I'm strong-willed. And I'm pretty much when I want my nursing, I said, I want this and I will get it no matter what. And I worked so hard. And I became an RN.

Tony: A lot of people we have interviewed have disabilities since childhood and yours is later onset. How do feel the difference in adapting?

Catherine: Well, you know what? I have people on my floor who have spina bifida, and I've asked them, because later on I did have to go to the wheelchair. They've been with the wheelchair since they were little. And most of the girls...the women who have the wheelchairs, a lot of them do miss walking. They would like to know what that was to play out there with the other kids and things. And the boys, they just brush it off. So, well, that's the way it is and, you know. But it seems like the girls it makes a difference. Because I think a lot of times...well, you know...well they were used to not walking so they should be able to take that now. But I'm...I walked. I walked for miles. I had so much energy and when that's taken away that's been the hardest thing. And then when I go to, say a wedding, I see people dancing. I'm like...So now I have gotten up and I dance with my walker in front of me. And if I'm dancing with a man I tell him the steps to take. I said, tell me when you're moving your foot forward so I can go back. And all the people with the spina bifida that I've come contact, they deal really well, you know. But the girls are a little bit more emotional about the past. And I like St. Jude's Children's Research Hospital, Danny Thomas, and I give to them because those kids

need to know what it is to be a kid. Because I was out playing all the time. Kickball and baseball and release and peg and so many of those kid's games. And I just really want those kids to live and know what it is.

Tony: Mentally how did you handle the diagnosis? Your faith got you through that?

Catherine: My faith did get me through but when I heard the doctor called me on the telephone and he just told me and at... The first diagnosis was an unsure. I'm like, either tell me I have it or don't type of thing. Well, I was crying so much that I had to be admitted to the hospital because I was vomiting and I was so emotional. And I was only there one day and then I said well, they said wait two months before another MRI scan to make sure. That's Magnetic Resonance Imaging. To make...And I was one of the first ones in Pittsburgh, the state, to get that. It was at Allegheny General I had the first...They just put the MRI scans in so this is the first time they really diagnosed somebody with MS. So the second one showed a little bit more of the white plaque. The white plaque is showing damage to the nerve. And a...They saw it. I'm like no. And they have a certain, not rules, they want you to have two plaques shown. They want you to show this many visible symptoms and you just can't do that. It's because MS just comes and goes all day. I was walking. I was getting tired today so my gait was getting really low. Now I'm in the manual wheelchair, which is great to sit down because I wouldn't be able to handle it. But it was really hard and, yes, I was upset and I'm like...My mother asked me about going to church. "No. Why? Why do I need to go to church. Look what he did. He's not helping me. I'm praying just like it says to pray, and you will receive through the son to the father..." So I didn't go to church for about a year or so maybe. Because it was just so hurtful. I felt God, but it wasn't God hurting me. It's just something that happened and actually He helped me have the attitude I have. He knows. He goes "Well you know, Catherine, you're the fighter and you can do this." And sure I'm...some reason He wants me to have this and maybe it is because I am only believing it now that I do make a difference, by me, my advocacy and things that I'm...I deal with for other people. I've been kind of like an example in what they can do and when they speak up for themselves, hopefully, and how you can make changes. And I have a friend, Ken, who works here are TRCIL, Three Rivers Independent Center and I got that backwards I know. Anyhow, he's been telling me for about 2 years "You know, you make a difference. You can do all that." And I haven't really listened to him. And so now I volunteer here once a week and I'm giving back and I have the respect of so many people here. And that's really nice. And I have respect that, yes I am a professional. I've been trained. I have education. And that treat me that. And they treat me as an equal. And that's a nice feeling. And it keeps me busy. I'm not having my mind on it. But I have to know when I can or can't work or if I'm doing too much. Because the next day I'll pay for it.

Judy: How often do you have flare ups?

Catherine: I used to have 3 or 4 a month...um a year. And they were horrible and they were very bad flare ups. And now from all the...

Judy: Medicine?

Catherine: Steroids.

Judy: Oh, steroids.

Catherine: From all the steroids has given me this long term side effects and one of those is osteoporosis and I have that. And I have been so blessed that with my falls I haven't broke a hip or any other bone. It's unbelievable. And then I have now reached cataracts. I'll have earlier cataracts. So if my parents had them I'll probably have them, too. And they...they just take the body and it takes so much out of the body and it's unbelievable how I am doing this well with everything I've gone through. Why I have such healthy hair.

Judy: I was looking at your hair. There's no gray...

Catherine: Yeah there is. Oh you don't have to look...Yeah there is. But I've been fortunate, my beautician, I've been with her for like 22 years, the same one. She's come to me when I needed her, and I go to her if she's on...she's at Station Square. And I've gone with her, Duane Else cut my hair, and now I'm letting it grow. And she goes, 'I just don't believe it. Look at you. I don't know why your hair is this healthy.' It's healthy, it's...I have too much of it if you ask and anybody would take my hair.

Judy: Did you have to have your head shaved when you had the...?

Catherine: No. Because they...When I had my adenoma, pituitary, what they did is they went up through the nose and then went in. So...

Judy: Mm hmm. It's amazing how they can do that.

Catherine: Oh yeah. And I had Dr. Maroon. And really what they thought but what dev...If...It was all about getting me off the ventilator. And when I woke up, he went "Okay." And I had to do some things to get off. And I was able to do it and I was alive. And this...not two years ago I had to get some stones out and they gave me a new treatment...well it's not a new treatment...

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That you go in and this sonic breaks up and he asked me to go under, under. And that's a big risk. But guess what? I did go under under and I paid for it because Dr. Hyman's nurse went, "You're a nurse. You know and plus you just know." And I'm like but he

was so...He goes I'd have to do this operation again, so...She goes, "Well that's why you feel like this right now and hopefully you will come out of it." So, I'm fortunate. And I remember when they saw that I agreed to it, the anesthesiologist and anesthesiologist, they were like. You could just see how they dropped in their facial. They're like, "Why is she doing this?" Because they knew not to do that. And they're like...So then I start crying because, I'm like, "If they can't get me off the ventilator, well, I better say good-bye to people." So I was saying good-bye to people by telepathy. That's what's it's called.

Judy: Mmm. Mmm. Mmm.

Catherine: And with the MS I have organic mood disorder. And you know what? That makes me emotional. And I was an emotional person to begin with so this just makes it even more. There is depression with MS. They pretty much automatically give a person anti-depressants, which I'm on, and I need some new ones. And that's the depression comes and goes and my depression is always changing. And I can be so high and within, if I get very tired and frustrated, then I get down.

Judy: Do you go out most days?

Catherine: Oh I try. Oh yes. Having a car. Because ACCESS. Everyone's like, "Well, you have ACCESS." But you know what? Can you make an errand to the jeweler by ACCESS? You can if you want to wait for that hour and have them pick you up, and that's if their on time. If you want to run to the post office, if you want to run to the bank it's very difficult. And so I...The people that come in I ask if they drive and they are reimbursed by the state for the mileage. And now it's .445 which, what it's like 4 bucks for a gallon of gas now.

Judy: So somebody drove you down here today?

Catherine: Yes, my attendant. And I told him, don't forget to put the miles down. So he came...brought me...He's the one who I go out to my mother's to give her her injection. Because I couldn't get Medicare to okay her being...home care nurse to come in. And then the doctor's started to kind of bicker between each other, with whose responsibility it was. And I'm like, "By the time this gets all done, she'll be done with all the..." So, I'm like, I'll take over and I'm going now every other day and give her injections.

Judy: So your attendant's with you all day?

Catherine: Mm hmm

Judy: What hours of the day? They work day, right?

Catherine: Yeah. Well, they come at 9:00 in the morning and the leave at 2:00. Then they come back from 6:00 until 9:00. And really I should take my shower then when they're there, but now it's summer and lights...And I'm...I take a risk, I know. I take showers by myself.

Judy: So you can get yourself in and out of the shower?

Catherine: Oh yeah. And I can dress myself and I'm very fortunate that way. Every once in a while I do have a problem with the bra. That's very uncommon for me. And when I have buttons, I don't have a lot of buttons, and sometimes I can do the buttons and sometimes I can't. And if I don't have someone there to help me, and I can't do buttons, that's what I don't wear. And I have to go wear something else. But sometime you know what? That gets a little aggravating, too. I mean...

Judy: What's that?

Catherine: That...

Judy: That you're able to something one day and not the next?

Catherine: Yeah, but you know what? That I have to change my wardrobe because of what...how I feel that day. And I'm like, I don't want to wear this. This is what a want to wear. I want to be dressier for that. You know. That's...And you know what? Did I tell you that I had braces, and I'm out of braces. Yes. And then it went on the next...I had two legs and they're called AFOs. And A-F-O, I can not think of the words for that, so sorry. So, I'm out of those and they like me staying out of them. Don't use those. So I'm throw...Actually just throwing them out now. I gave one to my doctor. And I was in the newspaper and didn't know. But I had...there's an article. With the *Tribune*?

Judy: Really?

Catherine: Yeah. And everyone when I go in the doctors. Ah, look at...Because I was interviewed. There's a picture of me walking with my...

Judy: How nice. How long ago was that?

Catherine: Maybe two years ago.

Judy: Oh wow.

Catherine: You can look me up.

Judy: Yeah?

Catherine: On the good old computer.

Judy: She'll do it.

Catherine: Okay. And then I also...the ARCs counsel interviewed me, too, and took my picture. Because that was the day before I was going to go swim with the dolphins.

Judy: Oh.

Catherine: So...And I didn't have makeup on that day but it didn't matter because it was black and white.

Tony: Yeah. Yeah. Right. Right. The medallion. Do the symbols mean anything on the...

Catherine: Oh this is Egypt. That's my name. And but it's not Catherine, because Catherine would be this long with all those...so...And then he's like...It was my brother-in-law who gave it to me and he said, "Then I call you Cath but I didn't know about that, so...It's Babe. But don't tell anyone, just tell them it is Cath." But no, I just had to tell the truth. And I have the little dolphin, because I love dolphins. And then I have my crucifix. I have my hot air balloon because that's what I like to do. And I have my nurse's hat, because I worked so hard for that.

Judy: Are you still in touch with your brothers and sisters?

Catherine: Yeah. I am. Sometimes I wish they could give me more help.

Judy: Do they live around here?

Catherine: Mm hmm. Oh yeah.

Judy: They all stayed around here?

Catherine: Yeah. They...Yeah. Some have. I'm going to California in the middle of May to see my brother and he's out there. He's always been away in different states, but yeah, when sometimes the family doesn't give help or encouragement or if they see that I'm doing real well, they won't say, 'Good job.' And sometimes, since I'm the youngest I look up to them and I want to please. I learned everything I do from them.

Judy: Do they come and see your parents?

Catherine: Yes.

Judy: Well that's good.

Catherine: Some don't. Some do.

Judy: So when you go to California how you getting there?

Catherine: Airplane.

Judy: Are you taking an attendant with you?

Catherine: No. I wish I could, but...no.

Judy: So...

Catherine: I'm on my own.

Judy: How are you going to get to the airport?

Catherine: Oh well, my attendant will take me. And then my friend, Ken, will pick me up. But this is going to be interesting. A long flight. And it's going to be different times. And I'm going to be...you know, I'm like, this is going to be interesting how I...And then I was just thinking now that I'll be in California, I won't have my wheelchair, my electric wheelchair. I'm like, "Oh no." But then I'm like, "You know what? I'm there and I'm not going to be worried about doing laundry and doing, you know, I'm not taking care of my home."

Judy: You can take your electric wheelchair on the plane.

Catherine: Right. But, you know what? There house isn't set up for it. And they have dogs running around. And now they have my great-nephews crawling around. So...It's just that way.

Judy: Yeah.

Catherine: Are we almost finished?

Judy: Yes we are.

Catherine: Because I have to talk to RSA. I have to be...

Judy: Oh, do you have to talk to them?

Catherine: Well, yeah, because I saw, I can't think of his name. He's the president of this board. He's...

Judy: Bill Pulman?

Catherine: Yeah, I think so. He's always in Harrisburg. He's African-American.

Judy: Yeah.

Catherine: Yeah. He goes, "You go in and you tell them." What, me?

Judy: Well, that's right. So I'm going to take your picture and you can go give those people from Washington what for. Come on little camera.

Catherine: Do I... Can I... Do I get to smile?

Judy: Yeah. You get to do whatever you want. Laugh. Whatever.

Tony: Is there any last words you'd like to give for advice to anybody or is diagnosed ?

Catherine: Well, you know what? It's...Just have to take each day as it comes and I'm the type of person who likes to prepare for the future and that's hard to do. And you have to trust in the Lord. And, guess what? That's hard to do because He's not visible, you can't...He's not somebody that you can touch and feel. So, that's...It's just...You have to have that. I think that's part...It has to be like a gene in a person to be such a fighter and it's not and you shouldn't really be pulling up yourself from your boot straps. You know. That's not the wrong way to think of it. They think, oh do that and everything is fine. No. And you have to do what...You have to speak up for yourself when things are going and if something's not right

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and you don't feel that it's right, speak up. When you're in the hospital, with nurses, with doctors, and you have to... Well, I was fortunately my own advocate. And if I wouldn't have spoken up because I was educated, because I'm a nurse and I know what's wrong, what's not...things. I have that luxury that I could say, you can't do this or whatever. But you really do have to fight for your rights, right now. And I just thought, oh well, disabled people are everywhere. Well, guess what? No. People are still...People actually, you know what? They told me how lucky I am to be able to park in the handicapped spot. They're like, "You are so lucky, especially at Christmas." I'm "What, excuse me." No, you know what? I'd walk a mile if I didn't have to park there. You know. You can't judge people. There's disabilities that you don't see. And they're like, "Oh look how well they're walking..." And I'm like, but you don't know. You don't know if it's a lung condition or a heart condition or orthopedics. You can't judge. But that's hard not to do. You know. I mean it's all the things you have to work on it every day. You have to work on it every day and you have work on thinking happy thoughts and good things around you. Make positive...Always have positive impact

from people. You want the positive people to be with you. That's how I feel. And they can bring you up. And sometimes they can be a little too hard, too. But, hey, not everything's perfect. So...Did I do okay?

Interviewers: You did wonderful. You did great. Yeah. Thank you so much. And you took a great picture, too.