

Interviewee: Marguerite Hamel-Nardoizzi

Interviewer: Alison White

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Transcriber: Alison White

Abstract:

Marguerite's interview brings a striking balance to living with and caring for loved ones with Huntington's Disease. Marg discusses the pendulum between being a spouse and, at the same time, a caretaker to her husband who is currently in the middle stages of HD while simultaneously balancing getting the most out of their days together and dealing with the emotional turmoil that HD leaves in its wake. Marg bravely discusses so many of the challenges a family faces when moving into the middle-stages of HD that are too rarely talked about.

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AW: This is Alison White. It is April 26, 2015, and I am here with Marg to interview her about her relationship to Huntington's Disease and how it has affected her life. Marg, how do you identify yourself as a member of the HD community? As an advocate, as a caretaker, as a spouse, what do you . . .

MHN: I'm a spouse of someone with Huntington's Disease. There are times I'm a caretaker too, but . . . I still am trying to hold on to more of the spouse role than the caretaker role, but . . .

AW: Do you mind if I ask how you do that?

MHN: . . .

AW: How you try to do that?

MHN: Yeah, I try to . . . I still try to work hard on my relationship with Chris. Trying to keep our communication, better. Chris, I think as his disease progresses, he becomes . . . there are times he becomes a little more, what's the word I want to say, he kind of lacks some initiation. I mean, it's part of the illness—it's nothing to do with him personally. And, and also, there's a lot of miscommunication at times, with someone with Huntington's Disease. They can say things or not say things that seem less typical of what you feel like they would have said to you in the past. So, anyway, just always trying to just, accept what I have to accept, what's maybe not going to be part of the relationship anymore. But, fighting for still feeling close, still, you know, holding hands, and still, trying to be partners . . . somewhat. Even though, as I said, things change over time.

AW: How has your relationship changed over the years?

MHN: Well, honestly, it was sort of like Chris rescued me. I think he told you the story, but . . . you know, I had been, I was the mother of three little kids. When my first husband left, I mean, my son was six months old, so I had sort of been through some not-so-great-times when I met Chris. And he was just so accepting and so sweet and he really, made my life, helped me so much, it was much more positive than it had been going. He was so great with the boys. The boys loved him. So, I depended on him a lot I think, and he's a very giving person, very kind. He's . . . you know, the way he treated my parents . . . I could go on and on about his kindness and his compassion for people and things like that. So, I really benefited a lot from all that over the years. It's like the pendulum has swung a little bit, and it's time for me to be more of that for him—which is fine. I want to do that. I would never think of not doing that. But there are times it's a loss for me, a little bit, because, you know . . . it's a little harder for him to remember all the time. Or just because of the things that are going on with him, he's not always as able to think about how something's affecting someone else, things that were very natural to him before. So, I miss that piece of him—but I remember that piece of him very well, so it makes it easier to, you know, still be there and make you want to give as much as you can to him.

AW: How, easy or difficult—what were the challenges realizing that your slowly sliding into a caretaker role?

MHN: . . . what are the challenges?

AW: Realizing that this is, realizing that these shifts are happening in your relationship—even though they're slight as they're happening, but it almost seems as you look from where you are now it's drastically different from where you were five, ten years ago. When you realize that's happening, how did you deal with those challenges, or how are you still dealing with those challenges?

MHN: It's an on-going process. Trying to live with some hope and live positively—get what you can out of every day while you're grieving. I mean, it's just, for me, it's those two—trying to have those two diverse things exist at the same time, if you know what I mean. Not to get swallowed up in the grief, but I can't ignore the grief. I don't, like, I'm not walking around crying all the time, but . . . You know, when I'm really sitting down to talk about it, I do, usually do get emotional and do cry, because for me there's a lot of loss attached to it. But at the same time, I know that for us to get the most out of what we have left, I have to be present to some of the joy that's in our life. So, really trying to look for that and focus on that as much as I can. Chris is much more glass-half-full, I'm a little more of a glass-half-empty—I never wanted to be, or identify as that, but it's just kind of how I've experienced life a little bit, so . . .

AW: How did you first hear about Huntington's Disease?

MHN: I don't know exactly, because I know that I already knew about it before Chris. I think it might be that my mother had a high school classmate that went on to have Huntington's Disease and she must have mentioned it to us a few times, because it was familiar to me when I first heard Chris' mother had Huntington's Disease. I was like, "Oh, I know what that is." The oddest thing is when his mother

got placed finally in a facility, we went to visit her and my mother's high school classmate was in the same facility.

AW: Oh wow.

MHN: Sitting right there at the table. Yeah, I'm like, "Oh my God!" I went over and talked to her because of course she, you know, knew who I was and all. And, like I said, Chris told you, he told me the night that we met about his mom, and that he was sort of her primary caretaker at that point, even though she was in—there was a hospital in Waltham at the time that had a big unit—and . . . I don't know, it was something . . . he was just so sweet and so kind and such a good guy, it was sort of like, I didn't feel like I needed to run away just because of that, you know what I mean? And two weeks later we went and met his mom—my boys, our boys, you know, grew up that we visited Judy in the hospital. I think, I think my sons, it was really hard for them because when Chris first, when we had to tell them that Chris had it, they really only related to somebody in the end-stage that they saw living in the facility. So, anyway. . . I guess that's it, I'm lost in what I'm saying.

AW: You've mentioned some of the day-to-day growing up with, growing up familiar with Huntington's Disease—at least at some point becoming familiar with it—how, you've kind of touched on this but, how has HD affected your life? Personally, how has it affected your day-to-day?

MHN: I think day-to-day it's trying to, like I said, trying to stay optimistic or look for what's going to be positive about today or something that we're going to make plans to do some fun things together. I have to be conscious of that because there's also the piece of me that can tap into sadness pretty quickly. I work as a social worker at Mass. General Hospital. So I work with patients undergoing loss or—I work in the intensive care unit—so I actually work with a lot of end-of-life situations. So, it helps me in my work in that I can tap into the empathy and those feelings pretty easily, but there's probably a downside in that it's so present for me all the time too.

Where I think, so it's a challenge for me every day to try to, like I said, see what's going to be good about today or take what I can out of the day and not just get lost in the sadness or . . .

AW: OK. What advice do you have for other caretakers or other spouses? Do you have any?

MHN: I don't know. You know, it's so interesting you'd ask me that because sometimes I wish I had advice from somebody else. I don't really have any connection to other caretakers, spouses of people with Huntington's Disease . . . or the little things that I see. Let's say I see things online or I read. I find that there's—what I end up seeing anyway is a lot of, you know, positive, really positive thinking, you know, "Life is Great! This is what we do!" My interpretation of it is, I feel like I fail in comparison to other people because it looks like they're so much more positive. I think they're coping with it better. It looks like they're into the hope for the future and all that, and sometimes I feel like, "Wow, I don't know if anyone would relate to me because I'm not necessarily at that place." And I think it would be helpful for me to talk to other people, sometimes, but I'm always afraid of, "Well, you can't go because you're going to be the wet blanket sort of on everybody else's positivity."

AW: First, I don't think that's accurate at all. I don't think that's true by any means. And, the what you're expressing almost seems like a sense of guilt for not being more positive when you can't be. We are dealing with situations that are challenging—there aren't cures—you know, you can make the most of your day, but we know where we're going. So . . . you know what's going on.

MHN: Yeah, I'm sure a lot of it is, but I think, like you said, there's a reality to it. And I can't imagine that other people don't feel it. I just . . . tend to read things, or the way it appears to me is kind of how they work together and how things are good and their hopes—positive things—which is great—I mean, I need that as much as

the other things. I just don't see the other things, and that's when I feel like, "Well, I should be more hopeful." It's something I put on myself I guess.

AW: What do you try and do to be more hopeful? Do you try, or do you just try and put yourself in a mindset and just hope it happens for the day?

MHN: I look at, I try to look at my whole life and not just focus on the Huntington's part. I always have to remind myself we have three grown boys that are happy and doing well and we have good relationships with. And that's so much. I want . . . these are the days of my life too, and the days of Chris' life with Huntington's Disease, but they're my days, my days I have to live to. So I want to make happy memories with my kids, I want to have a cookout and have them come over, and feel good and not—you know, the focus is not going to be on the fact that Chris has Huntington's Disease, you know what I mean? So, I try and look at the good things that I can still have in my life despite the fact that Chris has Huntington's Disease. Yes, we know how things are going to go, but we're not there yet. So, let's, as much as we can do, let's try to do it while he can do it—which we've done. We've tried to focus on some trips, or doing things with Chris that we know we want to do, and the time is now to do them. I guess we're very aware of that—to try to get it in—because you just never know.

AW: I'm going to switch gears

MHN: Yup.

AW: a little bit. How do you explain HD to people who aren't familiar with it.

MHN: I find that really hard, because it doesn't seem like people really usually get it. More recently there has been a lot of, I'm just seeing it in a lot of popular literature, trying to describe it to other people as a combination of Parkinson's, Alzheimers and . . .

AW: ALS comes up a lot.

MHN: Yeah, ALS. Usually they say ALS, Alzheimer's and Parkinson's. But I mean, even that's not really it, but it gives people a little bit more of an idea that all systems, like your mind as well as your body. Because, you know, when you sort of say it's a neurodegenerative disease, you go with just the clinical language I don't think . . . I think it's hard for people to really conceive. I think they get the idea that it's bad and they kind of want to change gears, you know what I mean? Or, "Oh, I'm so sorry," and move on to something else.

AW: OK. When you and Chris meet new people, how do you brood the subject, or do you at all?

MHN: Actually, if I feel like I want or need to tell them, and Chris doesn't mind—we might actually say, "Chris has Huntington's Disease." And, so, he might not remember everything the next time you see him so reintroduce yourself, something like that. And I'm getting more and more comfortable saying that, and I think Chris is fine with it. I think it's easier now in a way than it was when it was much more marginal—or sort of now though, people will say, "I, you know, I know he's supposed to be sick, but I see him and he's just fine." You know, it's different, very different, the lived experience. But, I think . . . [dog barking] . . . putting it out there . . .

AW: We're just going to pause for one moment.

AW: OK, we're back again. We were talking about how you and Chris meet new people and how that interaction is different than it may have been in the past.

MHN: There are times that we don't say anything and it's a social situation where you're just meeting somebody. And it's, you know, you're not going to spend the

whole night with them so you don't need to tell them. I . . . those are situations that are more anxiety provoking for me than if we're in a situation when we can just say, "Chris has Huntington's Disease," or whatever, because I get nervous sometimes when he'll, you know sometimes how people with Huntington's can speak a lot, get lost, go down a different track, you know all that kind of thing. I find that when we're in a social situation if that starts to happen with another couple that we're talking to I get so anxious, because I'm thinking about, "Oh, they're thinking, why's he going on like this? Or what's he talking about? Or now we're trapped!" I think all kinds of different things in my head about what they're wondering about why what's happening that they're not aware of. So it's easier for me in situations where people know. Like I said, it's not like Chris doesn't want people to know about it or anything, but for the first several years we didn't talk about it at all.

AW: You mentioned that new social situations can be anxiety inducing for you, and you talked a little about why. Is there, has that kept you from doing certain things? Or have you just gone through and plowed through them anyway?

MHN: Yeah, I think so. I don't think I've said no to things or we haven't socialized as much because of that issue. But there is a way in which it does change. I think we don't do as much as we used to do sometimes, and it's just some realities. Chris is very fatigued in the evening. So, you know, a lot of times he's ready to go to bed very early. Or . . . he can't drive anymore, hasn't driven for several years, so I drive everywhere and I have some back and neck issues and things—whereas Chris used to just, it didn't matter if something was three hours away, we'd go. There's times now I think if one of my sisters isn't going and can't drive us . . . so just some practical reasons too why we're a little less social.

AW: OK.

MHN: I think we both wish, I know he wishes he was in touch more with some of his friends and things like that, but it's just the way life has gone.

AW: Why did you chose to participate in the interview today?

MHN: So, I think Chris really wanted to. I think I knew it meant a lot to him, especially because he's so proud of his sister Lindsay—and of course I am too, you know, and her being involved. I think we want to support anything that she tells us about or is asking us about. And, but, I think he was probably more gung-ho excited and I was a bit more nervous because I know that I cry, and I know I'm emotional about it, and I know it's a source of obvious sadness for me—so I was worried, but I want to do whatever Chris wants to participate in and whatever makes him feel good.

AW: What are you most proud of Chris for?

MHN: . . . Chris is, he's just this really wonderful, sincere—he's so earnest, that's the other thing that struck me about him when I met him. Just, he's like, just a great, great person. Like I said, sincere, caring, he is . . . if he could sit here and talk with you, he's interested in you. He'll want to ask you things, want to know them. He's a really wonderful guy . . . and when he had to retire from his job after 25 years at the same company, they gave him a party like you can't even imagine. We called it his retirement, sort-of, and they said they were going to have a little party for him. We got to 500 Boylston St. is where he works, its this huge office building. We got there the night of the party, and there was an easel being put up in the lobby—and all of a sudden this enormous picture of Chris and it said, "The Man, The Myth, The Legend," on it. And we were just like, "Oh, my God, Chris. I think this is a big deal." It was in the board of directors room or whatever up on this gorgeous floor. The CEO of the company came, I mean, seven people spoke. And the CEO just said how if every employee was like Chris, your work would be awesome because it was like, loyalty, all these wonderful qualities. You know, not necessarily that he's the head business person, but just, all these really good qualities that you would care about. They knew he was involved in Make-a-Wish, and they donated \$50,000 in his name to

Make-a-Wish. I mean, it was just, such a tribute to him, and it was so deserved. That's just, he's like, sort of like . . . someone who's like—I'm trying to say he's not wonderful because he's the CEO of a bank or, you know . . . he's wonderful because he's this kind, giving person. And, I mean, everyone who meets him likes him. So, I've been proud to have him in my life, proud that he's my husband, he's such a great step-dad to our children, and he's just my friend.

AW: Who . . . who do you hope hears your story?

MHN: . . . I don't know, maybe there are other women, partners, spouses or whatever that, you know, maybe to know that there are people who really are able to kind of struggle through and that's its OK to cry and have a lot of emotion about it. It doesn't mean that your weak. Because I certainly feel like on the other hand that I'm strong for him. You know, I'm able to, life has gone on. I work full-time. I do everything I need to do, I've taken on more responsibilities, things like that. And, I think the piece, I think it will be interesting to hear other people, so maybe hearing how other people cope with struggling to stay somebody's partner in as many ways as you can as you're also becoming their caregiver or the caregiver role is becoming more and more . . . I know I've talked to his people where we go to at Mass. General—Dr. Rosas—and they'll say, "That's the disease talking," when I'll mention something that happened. Or this is where you've got to let go and realize you're the caretaker. I'm just not ready to completely let go and say I'm his caretaker—I'm still his wife. *Sam! [Speaking to dog] He likes to go into bags [to AW].* Maybe it would just be helpful for other people who want to fight to hold on to the pieces of my spouse that I can at the same time realizing there are other things he's not capable of and it's part of the disease and trying to find the balance that feels right. Just other people coping with it to know that it's not just black and white. You know . . . just because you're sad or have emotional feelings doesn't mean you're not able to deal with it or do what you have to do, and take care of him and make sure he has the best of everything.

AW: I'm done with my formal questions, is there anything else that you'd like to talk about that I didn't ask about or didn't come up?

MHN: No, I just, I guess I have to say that I did hear you and Chris talk a lot about the Huntington's community, and I have to say honestly that I don't feel yet like I'm connected with the Huntington's community like maybe I could be that would be more helpful for me, or that would be helpful for us—as a family dealing with it. I feel like we've been pretty isolated from, I mean, Chris does the things he does, which are fabulous. He told you all about them, but outside of that, there's no sort of personal connections, if you know what I mean. Like, we don't go to things with other families that have HD. I don't know if that would help or hurt, but I think it could be a positive thing. I don't know exactly how to make that work.

AW: OK. Well, that's I can recommend some things after we're done. Is there anything else? Actually, I do have a question. You said that you feel somewhat isolated from the HD community, do you mind expanding on that a little bit more? Don't think of HD as just HDSA, like, if you find it hard to network with other people who are in your situation, or . . .

MHN: We don't really know anyone else personally outside of Chris' family. And also, I think within families people deal with it very differently too. And, so, even within the family sometimes I feel in a different place, like I said, we just don't know anyone personally. I've heard there's a family in Milton, and I actually think I know who the woman is. It's not like we reach out to them or there's any way that we get in touch with each other—do you know what I mean? So, I think, I think it's more just I don't know anyone personally—we don't know anyone personally we're connected to that has it and I mean, we have heard some people speak at events, and you know, it's not any kind of a personal connection or something that keeps going over time. So . . .

AW: Anything else?

MHN: I don't think so.

AW: Well, Marg, thank you very much.

MHN: You're welcome.

AW: I appreciate you participating.

MHN: And crying.

[Laughter]

AW: It happens to all of us.