

## **CPI *Unrestrained* Transcription**

Episode 41: Marty Schreiber

Record Date: May 10, 2017

Length: 52:18

Host: Terry Vittone

Terry: Hello, and welcome to *Unrestrained*, the CPI podcast series. I'm your host, Terry Vittone. Today we have the privilege of welcoming our guest, former governor of Wisconsin and author, Marty J. Schreiber. Hello and welcome, Marty.

Marty: Well, good morning. What a pleasure it is for me to be here with you.

Terry: Thank you. Also joining us today is the director of sales operations for Dementia Care Specialists, a division of CPI, Virginia Pflanz. Hello and welcome, Virginia.

Virginia: Thank you. I'm so excited to be here.

Terry: Today, we're going to talk about *My Two Elaines: Learning, Coping, and Surviving as an Alzheimer's Caregiver*. This is the story of Marty's journey as a caregiver as Elaine's Alzheimer's progressed. And to begin today I'm going to start by reading just a little bit from the foreword of the book.

“The names of Martin and Elaine Schreiber will ring a bell for many in Wisconsin, especially political watchers. The story they know is that of the state's 39th governor and the first lady. Since 1962 when Martin won his first political race for state senate, they've been familiar faces on the political circuit, crisscrossing the state in campaigns for lieutenant governor, then for governor. They made an elegant couple, greeting Bobby Kennedy, President Carter, and other national leaders when they came to Wisconsin. For almost 30 years, election night usually found the Schreibers side-by-side watching the returns come in for one of Marty's races, accepting the victories and the defeats with grace.

Later, when his own political career had finished, Marty became one of the state's best-known government relations consultants. This was the story I knew in the beginning, the one familiar to so many, but it is not the one you will find in the pages of this book. *My Two Elaines* is instead the story of what happened to the Schreibers later in life when Elaine began to show the first signs of Alzheimer's disease and then gradually but surely came under its grip.”

So Marty, let's begin with our first question. In the preface to *My Two Elaines* you write that a primary objective was sharing your message man to man, but that people who reviewed the manuscript believed it could reach a wider audience. How did this specific idea of the man in the role of the caregiver spark the idea to share your experiences in the book?

Marty: I think it began with the understanding that I wasn't very bright and that I made any number of mistakes. Men don't like to ask for directions. We're heroes. We gather, we hunt, we do all of those things. And then when a loved one comes down and is diagnosed with dementia we don't realize what a challenge it is, and what happened was with Elaine's diagnosis, I think up until that point and maybe even today we failed to realize that there are two patients when there's a diagnosis with dementia. There is a person with dementia, then there is the caregiver. And we've got to understand that the caregiver must realize they can't do it alone, but they also have to understand more of the disease.

And so what prompted me to write about this is that if ignorance is bad—I mean if Alzheimer's is bad—worse than Alzheimer's is ignorance of the disease, and then going one step further, rather than worrying about the storm to pass, to learn how to dance in the rain. And I knew nothing about it and I feel guilty of things that I learned too late or not soon enough. I feel badly that we could, my wife and I, could have grabbed more moments of joy.

And it seemed that women as caregivers were better able to understand, yet many women have told me that this was extremely helpful. But sometimes we men are arrogant, we're self-centered, and we're too proud, and we think of ourselves as being too manly and therefore because of that we wanna do it alone and that's a disservice to the person with dementia. And also it's a disservice to the caregiver himself and to the family and to the loved ones.

Terry: In chapter 2, "When Marty Met Elaine," it begins with the sentence, "If you believe in love at first sight then I fell in love with Elaine Ruth Thaney in the fall of 1953." With that as a starting point, could you give our viewers some background and history on your relationship with your wife?

Marty: Well, it was Latin class and we were freshmen in high school. Thaney, her last name, Schreiber my last name. We sat next to one another and I looked at her and I said, "This is the woman that I want to marry. This is the woman I want to have be the mother of my children." And we of course dated and there were some times when we went to different colleges and universities, but through all that time we stayed together and married [at] now what would be considered an extremely young age, at 21, had 4 children, 13 grandchildren, 5 great-grandchildren.

And Elaine to this day still asks me how we met and I tell her, "Well, we met when we were freshmen in high school," and I said, "Not only that," I said, " I knew right away that I wanted you for my wife and not only that, I wanted you to be the mother of my children. And not only that, if any boy got within 50 feet of you, I bopped him on the head." And she looked at me and she says, "You're a BS-er."

In fact, you know, she loves me so strongly. The other day she told me, she said, "You know, even my parents are beginning to like you and I can't figure out why."

Terry: In the book's first chapter, "Diagnosis," you write that Alzheimer's doesn't stand still. Your partner will become someone you don't know, in this example the second Elaine, and you will become someone you don't recognize, a caregiver. I want you to talk about maybe the transformation that happens in that role.

Marty: If we can envision a funnel, and if we can put the small part of the funnel by our eye and we can look up and we can see the beauty of the sky and the hope of tomorrow. Now, what happens is as the person with dementia, as that disease progresses, that funnel begins to be inverted and then envision putting the same funnel to your eye and looking out and all you see is this small hole and that then becomes the life of the person with dementia. That's all they know. They don't know five minutes from now and they don't know five minutes past. And as this disease progresses it sort of shrinks the memory, it shrinks the memory from [I] can't remember five minutes ago and then five hours ago and five months and five years and so on.

And so it is the closing in, the closing in, the shutting down of the person's mind. And unless the caregiver understands that, everyone is in for a rough time because I no longer could expect of my second Elaine what I expected of my first Elaine. It would be foolhardy.

Now, one other important point, and that is [that] the same thing happens in the life of a caregiver. It's that same funnel. Early diagnosis, everything is sort of okay. You just have the diagnosis. You put the funnel to your eye and you can see the whole world with the blueness of the sky, the hope of tomorrow, everything is good. And as you become more of a caregiver, what happens is your life shrinks and it shrinks because you're so focused on—it's the anxiety, it's the depression, it's the grieving, and it's all of those things coming to bear. And as you focus more on one and you take care of your loved ones, that funnel again becomes inverted and all of a sudden all you see is right in front of you, and that's the person with dementia.

And once you get trapped into that, a shrinking world, all of your problems are greater, you lose perspective, irrational irritability, less able to cope not only with your loved one, but less able to cope with other ordinary things that you'd be able

to cope with in life. If someone tells you something and they're wrong, well, you can roll with it, but when you get trapped into that whole experience of your world shrinking, it's extremely unfortunate.

Virginia: Even as you were watching your first Elaine transition into Elaine as she is now, were there times then or are there times now where you still see glimmers of your first Elaine shining through that take you off guard?

Marty: Well, certainly, she's always gracious and she still tells me—they think for instance that she may be getting better, you know, you cannot reverse Alzheimer's, but they think in this case she could be in the process of being reversed because they hear her tell me how good looking and intelligent I am. And so once they understand that that's happening—you know, they heard her say that and they actually wrote an article for the New England Medical Journal about Elaine getting better. Well, then they needed one more proof and so they heard her call me a BS-er and then they knew that.

But by the grace of God, she has always been pleasant and kind, and always very complimentary. If she would hear a guitar play, for example, I don't care what the guitar player would sound like, she would say, "Oh, that's a wonderful guitar player." And if she would see a woman walking she would say, "Oh, what beautiful hair you have." So she's always been gracious, but beyond that, our communication is very limited.

She asked me many times how the children are and whether the children are at school and that's good enough. And so the conversations that we have are very close and just—there is no communication other than our hearts and souls touching and her asking questions about her parents or children and so forth which are sort of answered in a quick kind of format.

Virginia: So she's still concerned about everybody else? She's still concerned about taking care of everybody else in her life?

Marty: She is still concerned about doing that. This is a side note, but it goes to the point of how important it is to continue that touching of the soul. The other day, we were having lunch and she started to cry and I said, "Well, why are you crying?" Well, she says, "I'm beginning to love you more than my husband." And I didn't ask her what was wrong with her turkey husband, I didn't do that. But the point is that our souls were touching for the moment and that is all that was important.

And that is all that is important because, again, the life of a person with Alzheimer's, their life is just what is in front of them and because of that, I was right in front of her, she had the feeling of security, of being loved, and I felt good because it meant that our communication was working.

Terry: Since you're speaking of Elaine, I noticed that you wrote here that halfway or somewhat into the manuscript you found some writing of hers that you decided to include in the book. Could you tell us a little bit about that?

Marty: Well, that was sort of—I don't know if it was amazing, if that's a proper term, but we were ready to go to print and having been ready to go to print, I felt I had told my side of the story and, you know, I felt pretty good about that. Well, I find then some of her diaries and notes and journals that she had kept and I began to read them. And I felt terrible that I had felt so proud of the story I was telling and not getting into Elaine's side of the story. But when I read her journals and when I understood what was going on in her mind, we had cried together and we had prayed together during this course of time, but never did I understand the courage that it took for a person with dementia to continue on.

And I think if I could have understood just a little bit more, the courage that it took and her anxiety and her worry, I think I could have been a little more patient. And you know, when you go through this, you forget about the person going through what they're going through and all you're feeling are the constant questions.

We would go for a walk and we would come back and she would say, "Let's go for a walk." When we go for another walk, "I would like to go for a walk." Well, then you can't find, you know, some car keys and so forth and so it's the issue at hand that you become frustrated with, forgetting about the person. And so when she wrote those journals she had me understand more clearly what she was going through, but also so important in those journals is one of the reasons for the book. She talks about me, and some of these notes are in the book, about how I helped her. And I don't say that for self-aggrandizement. I say that so caregivers can understand that they are being foolish if they don't take care of themselves because the person with dementia is counting on them so much.

Imagine being diagnosed and knowing what your future might be, and then realizing that your loved one who is taking care of you is having some serious health problems. And those serious health problems come about because all of the emotions that are impacting on the caregiver, the lack of outward experiences because the caregiver's world is shrinking, they may not continue with their exercise programs. A caregiver of a dementia person is more apt to die sooner, more apt to become sicker, more apt to have his savings challenged or her savings challenged and so on.

So these notes that Elaine wrote, and she wrote one, for example, that she's not enjoying being my wife anymore. Another one she wrote in which she said, "I'm trying so hard. I'm trying so hard to be the mother and the wife I once used to be, but I can't do it and I'm beginning to understand."

And so I was fortunate to find those notes because I think it gives the reader a better understanding of the importance of the caregiver's health, but also an understanding of what the person with dementia is going through and therefore I think can put an entirely different light on it.

Now, I want to get to one other point which is not directly related and that is the book. I asked friends, dear friends and relatives, to look at the book in manuscript form. They said, "We had no idea what you were going through." And getting back to the question earlier about, you know, husbands, why for the husbands, well, because when Elaine and I would go out to eat with friends she would fight so hard to be normal. And in fighting so hard to be normal, at the end of the evening people thought I was the one who was having a little bit of a problem because they would call me up the next day and say, "Elaine is so good. You know, she's just doing so well." Well, I didn't have the nerve to tell them what was going on the other 23 hours of the day. I didn't have the nerve to tell them what it's like to be in that situation. So because of that, they never felt they could be helpful to me because I never asked them.

Virginia: Right. And they didn't maybe know what it took out of Elaine or what it took out of you to have that show for an hour.

Marty: Yes, that's correct.

Virginia: And then to go back to your real lives and to have that struggle and that frustration and, I mean, so much love, but also, you know, some of that guilt and tug-of-war back and forth.

Marty: Yes. If you take my situation, which has been extremely fortunate because Elaine is always gracious and kind and worried about helping other people, and also because we were long in years and also financially secure, but I know what I went through with those pluses. But caregivers are real heroes. Caregivers are truly outstanding individuals who are giving of themselves, their time, their energy and are almost unacknowledged heroes because nobody really understands what they are going through.

It's such a strong emotional experience to be losing your loved one, but then also going through your own psychological issues as well as going through your own health issues and so on that it does take its toll in so many different ways. And so it's my hope that if Alzheimer's is bad, ignorance of the disease is worse. Rather than worrying about the storm to pass, to learn how to dance in the rain. In other words, the more we can understand about this disease, the better off we are—everyone.

Terry: And I think one of the practical aspects of the book that I like quite a bit, in the introduction you ask the reader to let you be their trail guide, in other words, to share this experience as you look back on it. And one of the ways that you accomplish this is to include graphics of post-it notes throughout the book titled "What I Wish I'd Known" and "What I Wish I'd Done." And can you speak to those, why you included those in the book?

Marty: Well, again, things I learned too late, things I wish I would have learned earlier, and I made a note on a couple of these. Here's a post-it note, and again, this goes to all the caregivers. "I should have forgiven myself for not being perfect because I was doing the best I could in a difficult situation. It is understandable to have regrets about my shortcomings, but there is no point in feeling guilty." And that is a message for every caregiver.

"What I wish I'd done: By wishing for the past, I had deprived my wife of happiness in the moment. Even through it broke my heart, I should have let go of my first Elaine sooner so I could love my second Elaine where she is now." Maybe just one other to give the viewers a sense.

"What I wish I'd done: I should have worked to find a healthy outlet for my own sadness and fearfulness so that anticipatory grief would not limit my day-to-day functioning."

And so, you know, you're going through it now, but then there was also the anticipatory grief, knowing what's ahead. My dad would tell me, "Don't rush to meet the future," but you go through that and you do rush to meet the future because you know what the end result is of this type of situation. But these—I hope, you know, that it's possible for more people to—I call this disease not a chicken casserole disease because if you break your leg and you're laid up, I'll bring you a chicken casserole. But with Alzheimer's, people don't see that immediate disablement, you know. They just see this gradual—and then sometimes because they don't know about the disease, they begin to shy away again and then all of a sudden both the person with dementia and the caregiver become more isolated. The more they become isolated, the closer their world, the closer their world, the bigger the problems [seem] that are little.

Virginia: You also chronicle the process of going to a few different physicians, a few different specialists to narrow down the diagnosis. Looking back, do you wish that the diagnosis of Alzheimer's could have come sooner? Would that have made a difference, or made things better, or made them worse?

Marty: Well, I don't know if it could have come sooner because when—there was a test for Alzheimer's, and it's a very simple one. "Who's president of the United States of

America? Who's the neatest guitar player?" All those kinds of questions. "Which is the finest state in the Union other than Wisconsin?"

Virginia: Other than?

Marty: Minnesota maybe. But anyway, so they give you that test. So we had symptoms. Elaine was forgetting how to get to and from where she went for 15 years to work and help out at the Silver Spring Neighborhood Center. When she was backing out of the garage, she would scrape the side of the car, which was very unlike her. Her cooking, which was always outstanding, she forgot many ingredients or cooked too long.

And so there were those indications. Well, then when we tested her first, 30 or above on the score means that you're all right, 30 or below early onset. Well, she was at 28. And so I don't think earlier—she wasn't along that far that there could have been an earlier diagnosis, but many of the notes that I wrote in here about—one of the things I talk about is making a bucket list as soon as there is that diagnosis so you can continue to enjoy the kinds of special things, but then to also learn more about the disease so you know how to handle it. And one of things which is—you can't argue with Alzheimer's. If Elaine has five coats on and she's cold, she's cold and no discussion in the world is gonna convince her that five coats is enough. It's so easy to get another coat.

Terry: As you just spoke now about how caregivers can sometimes let isolation take them over, one of the "What I Wish I'd Done" notes says, "Right away I should have taken full advantage of all that the Alzheimer's Association has to offer. Besides support groups, there is individual counseling plus online tools and information." How did the Alzheimer's Association help you, in your words, "pull it all together," so you could be an effective caregiver and learn, cope, and survive?

Marty: Well, the Alzheimer's Association is still helping me pull it all together, so to speak, and it's not because they're slow on the uptake. It's because I'm still going through the process, and it's a journey, and they're still helping me in my new capacity as sort of an administrator of caregiving rather than a director of caregiving. But by going through counseling they helped me understand some of these things like you can't argue with Alzheimer's. They helped me understand how important therapeutic fibbing is.

And Elaine was very concerned about her parents. She asked me how they were. I said they're both dead and the shock on her face when she realized that she hadn't properly said goodbye, and so I promised myself I would never allow that to happen again. But the Alzheimer's Association helping me understand the disease, now if she asks me how her parents are, I say, "Your parents are fine." And I said, "Not only that. They're at church and they're happy." So that's therapeutic fibbing.



And then also not getting involved in the battle of Alzheimer's, "You should do this or that," you tell your loved one. "Well, why?" Well, not, "Because I said so." You blame it on someone else, "Because the doctor said so." If there's keys that have to be taken away for the car, "The doctor said we should be doing that." If it's good for you to be at a certain location, "The doctor said you should do that." So blaming someone else. Blaming someone else and therapeutic fibbing, if I would have thought about that when we first got married, can you imagine how happy of a married life we would have had because I would have been able to come up with all of those? Or even when I ran for governor back in 1978, you know?

But the Alzheimer's Association—and it's not only the counseling [that's] directly there (24:20), but you meet other caregivers and you understand what other caregivers are going through. And what happens is you develop—through the Alzheimer's Association and going through this journey—you develop a whole new set of friends. Not that there was anything or is anything wrong with the friends before Alzheimer's, but it's a different life. And so as the journey continues, you get into this new world and this new world is of people like yourself who are trying to cope and learn and survive, and sometimes thrive on the disease.

As you get to that point, your world begins to open up, and you become more at ease, and you become more understanding. You realize you're not the only one, and you learn other kinds of experiences that people are having—you know, you learn more about how important music might be or you learn how important art might be. I mean if it wouldn't be for the Alzheimer's Association, quite frankly, I don't know where I would be physically, health-wise, as well as just being able to survive.

Virginia: Well, in developing that community of people who are in a similar situation to you, I'm sure you're able to identify with each other in a way that other people sort of peripheral to the situation just can't really understand, not fully.

Marty: Yes. I want to give you the same example in two instances. Same example. If we think of an insect with the feelers and how sensitive they are, it seems that the person with dementia has so sensitive feelings that because their world is so small, which is right in front of them, their feelings are so much to the surface and to the now that they're ever more aware of uncomfortableness or anxiety or fear by the person who does the visiting.

But with caregivers, it seems that there is a special antenna, a special kind of sharing of feelings, which brings people closer and also a more understanding of what each of the parties are going through as it relates to their journey. And so yes, I may have an old friend from prior-Alzheimer's and it's a friendship, but nowhere

near the kind of, again, touch-in as I might have with another caregiver who is going through the same journey that I was going through, am going through.

Terry: You say in the book that you wish you had reached out sooner.

Marty: I wish I would have reached out sooner. There's any number of different things. First of all, to understand more about the disease, I mentioned the therapeutic fibbing, the need to let go of my first Elaine, which is difficult but extremely important. There's a chemical in the body called cortisol, and cortisol is released just before your body releases adrenaline when it comes to flee or fight. And when you're under stress as a caregiver is, your body releases more cortisol. And cortisol—too much in the body can have very disastrous results.

One of the least is which sometimes dementia, and not Alzheimer's, but a form of memory loss. But also this adds on extra weight to the body because the body is getting ready for this fighting or fleeing, and we better make sure we've got these extra calories along. And so I missed all of that information, and I didn't understand what was happening to me.

I did have a mentor at the Alzheimer's Association and I said, "Do you ever sometimes just feel like screaming?" He says, "Not only that, but I actually scream." And just hearing that other people were going through that same kind of experience made a big difference in my life because now I understand that I can't feel that guilty of my anxiety and my frustration and lack of patience because other people are going through it too. But then I wish I would have known sooner the importance of joining my wife's world, of knowing that her world, as I thought it was, no longer exists.

And I wanted to share, we gave a book presentation at Barnes & Noble, and in the audience was a woman by the name of Lisa who was about 45 years old. And she told me this story. And she said that what happened was her mother called her and says, "You've got to come home right away because Dad, who had Alzheimer's, is acting really strange." So she rushed home. And here in the middle of the living room is her dad. He's casting and just throwing it out and reeling it back in. So she said she stood beside and said, "What are you doing, Dad?" He says, "I'm fishing." "Well, what are you fishing for?" "Well, I'm fishing for walleye." "Well, can I join you?" He says, "Sure." So then she started casting and reeling in.

And she said that in the years that her dad had dementia, that was one of the most worthwhile experiences that she has had in touching with her dad. And so now she's leaving, her mom says, "What do I do if this ever happens again?" And she said, Lisa told her mom, "Get in the boat with him." And I wish I would have learned sooner, you know, the idea, the importance of joining the other person's world and getting in the boat with them.

Sometimes behavioral issues of people reacting is not necessarily so much the impact of the Alzheimer's as it is the impact of the person with dementia not having whoever is there not being in their world with them. And you know, I shouldn't argue with my wife about whether or not five coats or six coats is enough, I shouldn't argue with my wife as to whether or not she actually has bugs on her arm when she feels it in the middle of the night rather than redirection. And I guess a survivor, in order to survive, to understand you can't do it alone, and to try and join her world as quickly as you can, and it's so very, very painful.

Virginia: So then your experience has been that Elaine communicates through her behavior?

Marty: Elaine absolutely communicates. You know, one of the things that I learned from the Alzheimer's Association—Lynda Markut is my counselor and she said, "Now, what's bothering you?" And I said, "Well, I feel so guilty because I didn't want to go see Elaine and I feel guilty." And she says, "Don't." And I say, "Well, what do you mean don't?" "Well," she said, "Elaine or a person with Alzheimer's, their world is so much in the present that they can sense and feel what is going on immediately in front of them." So if I come in with anxiety and worry, she picks up that anxiety and worry. And so if my goal is to make her feel comfortable and relaxed, I am accomplishing exactly the opposite by going in when I'm anxious and nervous because she picks that up.

And so this whole issue of communication, like her telling me that she loved me more than her husband, that whole issue of communication, getting the hands and the heart to touch is more important than anything that they might say about anything.

Terry: It's interesting that you note that those emotional antennae are so much in the present. And in the chapter "Being a Real Man" you write that, "When a man is put into the position of being a caregiver for his wife, he'll do so with a broken heart. And he will try to carry that weight alone." I mean how did you—did you try to mask that heartbreak then? Or how did you manage that emotion with Elaine?

Marty: Well, I don't know if I did manage that emotion very well in the beginning. I bought a lot of roses and a lot of boxes of candy for people that I became irrationally irritable with. And again, to go back to the funnel and to what's immediately in front of you, my world was closing. A person who has a very closed world is more apt to be offended quicker and lack objectivity and feel more put upon. And so, again, if it would not have been for the Alzheimer's Association, I wouldn't have understood how important it is to share.

And again, we men are not very bright. We don't like to ask directions, but we also don't like to show our emotions, whether it's the loneliness or it's the heartbreak. And so finally, in my situation, my health was so bad that people said, "Look at you.

You've got to do something." And so once we figured the health issues and then also the emotions of going along with this—with the anxiety and the grieving and the heartbreak—once we sort of got that squared around, life has been a little bit easier. But there again, I want to emphasize that caregivers are real heroes and that they're going through heartbreak and all of the other feelings and emotions that I described. And because of that, they're just outstanding, courageous people.

Virginia: You referred to yourself at one point in the book as "a widower with a wife" which I could see some people sort of thinking, "Oh my goodness, that's a big thing to say." But I imagine that is something that resonates quite a bit for people who are caregivers like you and for people who are sharing that experience.

Marty: My first Elaine is gone. And with all the pain—and so because she's gone, I just have to move on. But she's still my Elaine, and so it's almost like I have two Elaines, the one that I married and shared my life with, and then another Elaine which is maybe mentally three to five years old and [I'm] still married to both Elaines. And I never begrudged that.

But one of the things that really is a challenge and I think one of the reasons caregivers have such a difficult time emotionally, and I want to be very careful how I say this because I don't ever want to hurt anyone or offend anyone. But if there is a sudden death by heart attack, there is an immediate acknowledgment for the grieving, and there is almost an immediate closure because you know for better or for worse that person is gone, and because of that, life, better or for worse, continues for those who are surviving.

With Alzheimer's, there are many times there's not the acknowledgement because people really don't understand what you're going through, but then there also really is never closure. It's a constant kind of changing and watching this person devolve. And I won't use the word evolve, but change into someone different. And so you don't get that closure, and so you try and work it out as best you can. But I think if more of us caregivers could understand that somehow or other this whole area of bereavement is something we have to work about coming to grips with because the better we can handle that bereavement, I think the better we can go on with our lives, but also the better caregivers we could be.

Terry: You know, in the chapter speaking to that, "Living in the Now," you write about your way of your phrase "slaying the dragon, choosing to see Elaine as the person she is now, the second Elaine." That's an interesting choice of phrase, especially when you don't have the support, like you said, of someone who has a family where they suffer an instant mortality. How did you slay the dragon day to day?

Marty: Well, I'll tell you how not to do it. All of the armies marching and all of the navies sailing and all of the beer brewing and all of the whiskey distilled is not gonna do it.

It's not gonna slay the dragon. And my daughter, Kristine, gave me an article on moderate drinking and it . . .

Terry: The caregiver's poison, I think.

Marty: Yeah. And she didn't give me the caregiver's poison, but she didn't give me the article on moderate drinking because I was drinking too little. You know, just quite the opposite. And so I think it was certainly—I tell the story about the hippopotamus and the butterfly that fell in love. And they're gonna get married and the hippopotamus is beginning to think about the consummation of the marriage. So he seeks out the wise owl and he says, "Wise owl, I'm gonna get married. We're gonna have a honeymoon. We're gonna consummate the marriage. You can see that that's gonna be really tough. What do I do?" Well, the wise owl says, "What you have to do is turn yourself into a butterfly." And so what happened is the hippopotamus accepted that advice and walked away. And then it dawned on him this was pretty impossible, so he says, "Wise owl, how do I turn myself into a butterfly?" Well, the wise owl says, "Get lost, buster. I just determine policy."

And so I mentioned that story because how does one cope, you know, with the second Elaine? How do you slay the dragon? This is policy because it's almost impossible to get to the point where you let go of the first Elaine. So if she doesn't know me anymore, that's okay because I know that this is a different Elaine. If she doesn't recognize the family, if we're getting together at Christmas time and all of the family is there and she tugs my shirt and she says, "Who are these people? And let's go home. I don't want to be with these strangers."

So you work on slaying the dragon by understanding more about the disease and you work on slaying the dragon by understanding that this wonderful human being still loves you in their own way and still tries to communicate with you in their own way and, if at all possible, to embrace that new person.

Virginia: And as you were saying, to still have that connection and that hearts and souls touching. That part at least is not diminished by all the other trappings around it, right?

Marty: And in fact, really when you say other trappings, basically there are no other trappings. I mean that is what life is all about for us now, and that is for our hearts and souls to connect.

Terry: You write in the book that when your partner gets an Alzheimer's diagnosis, it's important to make a bucket list. And I'm wondering what was on yours and if you could speak to that a little bit.

Marty: Well, what we did was I always wanted to go—and this was an interesting thing. I always wanted to go down to Miami, Florida and on the way back—and so we did that, but on the way back we stopped at a friend's home who were our friends since college because this goes back to 1960. And so we happened to see them. It was Elaine's closest friends and we were able to understand that we could have a good communication with them. But the bucket list just simply had us do—making sure that we visited the grandchildren, making sure that we did all the things that one would ordinarily put off in ordinary life because they're too busy.

Terry: When you knew that the time had come for Elaine to live elsewhere, explain how the Alzheimer's Association's assurance that you were not "putting her someplace" helped you with that decision.

Marty: This question is one of the most important questions that we get in feedback sessions as I travel around the state and talk with different groups. There's so much guilt, but there's so much self-pride about never putting their loved one in a nursing home or an assisted living. And I think that is a devastating downfall for the family as well as for the person with dementia.

So I'm visiting with my counselor and I'd say, "My health is being dragged down. I don't know how I can cope. I'm almost at wit's end." And I said, you know, "My friends are saying, 'You've got to do something.'" So I talked to the counselors. "I cannot see putting Elaine into a home," and the emphasis of course being "putting." And so she said, "You're not putting Elaine any place," and she didn't come out and say that I was maybe self-centered and selfish and of a nature of being too much with pride. She didn't say that directly, but I came to understand that. And what I came to understand is that maybe I was wanting to keep her for my own benefit because I could not feel bad about putting my wife into a home, well, again, "putting."

Well, Lynda said, "You're not putting your wife any place. What you're doing is you're giving her an opportunity to be who she is now." And there was no way that Marty Schreiber 24/7 nursing home facility could do anything to help Elaine be who she is now. And with trained staff and activities going on, better meal preparation—as I mentioned before, we would go out for a walk and we'd come back and Elaine said, "Let's go for a walk." We'd go for a walk.

So I am a better person and can give more to my children and grandchildren, and Elaine is happier because she has less anxiety because I feel less anxiety. And so I want to tell anyone that they cannot be fearful about giving their loved one an opportunity to be who they are now by admitting that they may not be able to give that kind of help.

Virginia: Marty, you don't go into too much detail in the book, but I could see that some of the other caregivers who are watching or listening would benefit from knowing more about how you chose a new home for Elaine.

Marty: A very important question, and I think the most immediate response would be to understand the opposite of "stone walls do not a prison make." In other words, if you are looking for a living situation for your loved one, I think certainly when you visit what you wanna do is the nose test. It's as simple as that. What is the aroma, you know, in the facility? And to forget about the fact that there may be a crystal chandelier and solid oak wood floors and so forth. The question is as you walk through this facility, what are the programs that they have? Take a look at that and sit down and have a meal and see once what the food is like, but then also see the personality and the characteristics of the person who is maybe in charge: what kind of personality do they have? And then if that's a loving, caring personality, does that go to the people who are on the front lines?

And I'm gonna tell you that a caregiver—a licensed practical nurse or a caregiver—is doing at very, very modest pay what someone would not do for \$200 an hour. But yet they, many, give the kind of love and attention. And so when I have to say goodbye to Elaine and one of the caregivers there can take Elaine, "Okay, Elaine. Let's go. We're gonna do just a little bit of a dance," or, "Let's go. You can help me pour coffee or help." And giving Elaine a feeling of worth in the redirection.

And so when one looks for an opportunity for assisted living for a loved one, again, to look at what is—there's a sense and there's a feel and there's a smell test, I think, which is just most important, looking at the activities, but then also these homes are inspected by the state. And there are certain rules and regulations they have to follow. They should have an inspection report available for one to look at, and if not, you can go to the Department of Health and be able to get a report on that.

But my suggestion is to look at two or three of them and not go alone because if I, for example, go and I know I'm biased for—let's just pick one out, guitar playing. I just have a bias for guitar playing and I'm looking for a place and there is some place there I go and someone is playing a guitar, I may say, "Well, that's the place for Elaine." Well, no, I've got to be going with someone who can help me give these kinds of balances and ask a lot of questions.

And if you can bump into some of the loved ones of the people who are there and say, "How is it going?" and again, you'll watch the interaction. And again, a lot of the behavioral issues sometimes come about because people don't understand the disease and they're not getting into the world with the person that has dementia. And if they don't understand it at that home, you know, that's tough.

This is a quick story. A man comes across a body in the road. It's very seriously hurt. He gets on 911 and he says, "You have to send help right away." He says, "There's a body. He's very ill, very sick." And the dispatcher says, "Where are you?" Well, he says, "Well, I'm on Pistachio Street." He says, "Okay." He says, "How do you spell Pistachio?" He says, "I don't know how to spell Pistachio. Just send help right away." He says, "I'm not gonna send any help until you spell Pistachio because I've got to make sure it goes to the correct place." Well, he says, "Send help." "I'm not gonna send." "Okay," he says, "I'll call you back in five minutes." Well, "Call back in five minutes?" says the dispatcher. "How come call back in five minutes?" Well, the man says, "I'm gonna drag the body over to Elm Street."

And if the assisted living facility memory care does not know how to spell Pistachio, if they don't understand the disease and all the different kind of variations of helping through redirection or therapeutic fibbing or joining that person's world, if they don't understand it, I think there's hell to pay, not only for the person with dementia, but their family and even for the staff as well.

Virginia: So you would recommend to anybody who's touring these communities to look into the training that the staff receives?

Marty: It's very important that they get a sense of understanding the disease, yes.

Terry: Well, to close today, Marty, going back to the title of your book, *My Two Elaines: Learning, Coping, and Surviving as an Alzheimer's Caregiver*. There seems to be a mantra in the book almost, "learn, cope, and survive." Could you speak to those three words, those three ideas, and why they're all connected and important?

Marty: Sure. Well, let's go back to learning how to spell Pistachio, to learn more about the disease. And it's not anything to rejoice about, but the learning comes about with, again, rather than worrying about the storm to pass to learn how to dance in the rain, to learn about the disease so you can help play a role with your loved one in getting through this journey.

Coping. My goodness, if I wouldn't have had an understanding of how to deal with some of these very frustrating aspects, I don't know how I would have been able to cope. And if you can't cope, you can't survive. And anecdotally there are any number of caregivers who have not survived and have gotten a heart attack before their time and who have deprived their family and friends and their loved one of an opportunity to take a leadership role or to be a caregiver and so forth.

So surviving is quite important for the caregiver then for all, but then also I'm thinking of another point and that is thriving. I don't know how it's gonna be possible to thrive, but I think we caregivers have to look at not only learning and coping and surviving, but also somehow or another thriving to begin to rebuild.



And thriving for me was writing the book. Thriving for me is sitting here and talking with you about how we might be able to impact on people's lives through the positive and so that's thriving for me.

And another one of my brother caregivers bought a little springer spaniel called Scooter. So his thriving is bringing this cute little puppy into the assisted living and the people love him, you know. Another caregiver gets some puppets and [performs] shows with puppets, but somehow or another we—again, I want to get back: if there's one thing worse than Alzheimer's, it's ignorance of the disease. Rather than worrying about the storm to pass to learn how to dance in the rain, and again, that dancing in the rain is to learn about the disease, but try to figure out how a caregiver can not only survive but thrive.

Terry: All right. I'd like to thank my guest today, Martin Schreiber, former governor of Wisconsin and the author of—and Virginia Pflanz.

Virginia: Thank you so much.

Terry: Director of sales for Dementia Care Services here at CPI. Martin's book *My Two Elaines: Learning, Coping, and Surviving as an Alzheimer's Caregiver* is available on Amazon.com. There's also a website.

Marty: Mytwoelaines, all one word, and they might be able to order through that website as well, but it's mytwoelaines.com, and again, all one word, two spelled out.

Terry: Great. Thank you for joining us today.