Full Transcript of The D-Word podcast with host Peter Hill snd Mark Steven Porro

[00:01:22.050] - Peter

Hi, I'm Peter Hill, and this is the D word, the show where we talk dementia. Welcome along to our first new channel of 2024. My guest this week is Mark Steven Porro, a Hollywood actor, producer and director whose life changed dramatically when his mother's health started failing. Mark's story is told in the book, "A Cup of Tea on the Commode." And we'll be finding out all about it after this.

[00:02:06.390] - Peter

This year that kicks off this week's edition of the D Word, where my guest is Mark Steven Porro.

[00:02:13.290] - Peter

Well, Mark, it's great to meet you and welcome you to the d word. Plenty to talk about, particularly the book, which we'll come on to. But you had a successful career going. You were over there in Los Angeles, and then suddenly your life changed dramatically, didn't it? I mean, just tell us a little bit about the story.

[00:02:37.590] - Mark

Well, okay. So at 55, I was a carefree bachelor. I was a carefree bachelor 54 years before that as well. But having a good time, enjoying life. They say I had commitment issues. Okay, I may have to cop to that, but I had a business and I was an actor, but I was aging out of acting. And so that career was slowing down. But my snack food company business was booming. Not booming, but it was very time consuming. And then I got a call from my brother who said, our mother just kind of shut down, and she was living in the house I grew up in in a little town, Ridgewood, New Jersey. And he said she just shut down and seemed to be very depressed and almost seemed like a self-induced coma. And so he put her to bed and called the doctor. The doctor cut off all meds and food and said, she's going, so let her go. And then hospice was called. And I freaked out a little bit because hospice was called 14 years earlier for my dad, and two days later he died.

[00:03:57.260] - Mark

So, I flew in the next morning. Mom had six children. I'm the fifth, the youngest of three sons. I have one younger sister and two older sisters. We all came and we came to say goodbye. It seemed like she was going. We had a priest come in and give the last rites. But my younger sister and I stayed with hospice and learned as much as we could because we didn't know how long Mom was going to be with us, but we wanted to care for her as much as possible. So we wanted to learn from the pros, so we stayed on. It was basically a waiting game to see what was going to happen. And she didn't open her eyes. Very infrequently, she opened her eyes, and she stared at a spot in the corner of her bedroom but didn't speak any words. And then a few weeks later, again, no food. Maybe a little moisture on her lips to keep her

mouth moist, but that was about it. She would respond a little bit to touch, but didn't talk at all. And one of the hospice nurses broke the rules. We found out that several of them break the rules, but this one actually did a good thing.

[00:05:13.640] - Mark

She went in and asked our mother again, lying, eyes closed, and she said, are you hungry? And my mother's eyes opened up for the first time in weeks. And then this nurse accused us of starving our mother to death. So we got very upset with her, and we said, go call your supervisor because you broke the rules. And the supervisor told her to leave because she did, in fact, break the rules. But now I'm thinking, oh, my god, are we in fact starving our mother to death? So I went in and asked her if she was hungry, and she said, what do you got? And again, it's the first words in weeks. And I said, anything you want. And she said, well, how about some pumpkin pie? And it was march at this point. This whole thing started the first week of February, so now we're into March, and it's not quite pumpkin pie season, but my brother lived locally, and he took the challenge on and went out and miraculously came back with a couple of pumpkin pies. And so we gave her the first bite, and she spit that out because that was the first food in weeks.

[00:06:24.110] - Mark

We said, well, that didn't go so well, but we tried again, and it went great. She ate half the pie the next day. She finished off the next half and the second pie, and then she moved on to Sherbet and then moved on to oatmeal. So it wasn't the best, I would say, food choices. But she was back. She was alert, and she seemed happy that her kids were there. And in the book, I write a chapter about a silent scream, and I think it was a cry for help. She was depressed, not happy with the current situation, even though she was in her home. I think she wanted to be surrounded by love. That all changed from that point. My life kind of changed, too, because I didn't move back right away. I stayed with her for a few months, and then I think, started to think about, my mom deserves better, so I've got to make some moves. So by the end of the year, I moved back into my childhood home and that was that.

[00:07:33.410] - Peter

You moved, obviously, back into your childhood home. I mean, how difficult was it at that stage? Because you kind of always brought up, our parents are going to look after us, and suddenly you got this whole role reversal thing going on, haven't you, in the fact that you are now the primary carer.

[00:07:52.010] - Mark

Yeah, well, I left when I was just after I turned 18 to go to college and never really moved back in. But we had people in the house that were overseeing household duties and things like that. They were doing shopping and cleaning and laundry and stuff for my mom at that point, my mom could walk. She went to a senior center during the days, but she was kind of dependent on them and I think they did not get along

so well. So I moved back in. I hadn't had roommates in decades, and now I have roommates, A family of three generations that were living upstairs. And so that was probably the most difficult part because I had to deal with them. We had to make an arrangement that was agreeable with all the siblings. So my choice would have been to get rid of them pretty quick, but we let them live in our home basically rent free for another six months. So I had to deal with that. So that was very stressful.

[00:09:05.440] - Mark

Once they left, then it was just me and Mom, and things got a little better. But, yeah, it was quite a change. But I was open to it, and I think that was a big lesson that I learned. I went in saying, okay, my mom deserves better. I've got to make that happen. And as difficult as it's going to be, that choice was simple. The logistics were a little more difficult. But early on, I told my mom, I said, listen, if I do this, I asked her permission. I said, you want me to come back and make sure you're treated well? And she said, yes. And I said, okay, if I do it, I'm in charge at that point. And then her mood completely changed and I said, you must obey me now. And she puckered up for a kiss, and I wasn't sure if that was a sign of surrender or one wishing me luck, and so I gave her a kiss and hoped for the best.

[00:10:00.250] - Mark

My goal was to make her laugh at least once a day. And luckily, both of my parents were pretty funny people, so we had a lot of humor in the house. And so she was fun. We had a lot of fun. I mean, my goal was to make it fun, and I'm pretty good at doing that. And I grew up that way with my folks. Any crises or stuff like that, we kind of handled it with humor as best we could.

[00:10:32.250] - Peter

I'm chatting to Mark Steven Porro about his book "A Cup of Tea on the Commode," which is certainly one of the best titles I've come across.

[00:11:13.340] - Mark

Well, that's funny because Mom was a coffee drinker until she was expecting me, and she lost a taste for it. So she switched. Her favorite beverage was hot tea, skim milk, no sugar. And at that point, she couldn't walk or anything. So we set a commode next to her bed, and sometimes mother Nature took a little longer than was comfortable. I wanted to see if I could make her more comfortable while we waited for things to happen. And so I offered her her favorite beverage and she said yes, and I gave it to her and it became a hit. So every day she got a cup of tea on the commode.

[00:11:58.790] - Peter

It's a great title. And in terms of, I mean, tell me why a book? I know you've had a career in kind of media, acting, etc, but you've gone through a pretty tough time, obviously, as well as having a lot of humor with your mom. Why and when did you decide you wanted to put all that down?

[00:12:20.750] - Mark

Well, I've always enjoyed recording family history and monumental moments in our family, so that was kind of in me. And I always did this as a kid, I guess. And when we had family reunions, we would get together for, I think we did this for 13 years. The whole gang, three generations, spent a week at various locations, mostly in eastern United States, and I would write a poem, summing up the week. And then when people had big birthdays, I started originally with my dad. When he turned 75, I gave him 75 memories, and then with my mom, 75 memories also. And then I invited my siblings and other relatives to join in and add memories to other people's birthdays when they hit like 30, 40, or 50. And then I took my dad to the little village where his father came from in Italy, and I shot a documentary of that so people could discover the same things we discovered. So when I was there with my mom, I always took notes because I didn't know what I was going to do with it. But even with my dad 14 years earlier, I was with him only for eight days before he passed.

[00:13:35.050] - Mark

But I took a lot of notes, and I said, I'm going to do something with this someday, whether it was going to be a screenplay, a poem, a short story, or what. And that will be the focus of the next book, will be more on my dad. But this one, I just took notes, shot a lot of videos and a lot of photographs, because there were some very poignant and fun conversations that we had that I didn't want everybody else to miss out on. When you're doing 24/7 care, you get these moments you may never have again. And I didn't know how many of those we were going to have, so I recorded all of them. And then a few friends found out what I was doing, and they happened to be dealing with the same situation. So they were asking me, because they didn't do the. They asked me for advice and stuff, and so I helped them. And then I said, if they're getting some benefit from this, I think we have something. There's got to be a lot more people who could benefit from these stories. A book seemed to be the thing, the best to get out there.

[00:14:46.250] - Mark

So there we go. So I never wrote a memoir before, but I studied the craft, and it took a number of years to write it. I needed distance, so I moved to France in 2016, a couple of years after my mom passed. And I'm a very emotional guy, and obviously it was a pretty emotional ride, but I needed distance before I could sit and write without bawling all over the place, which I still did seven or so years later. But that really helped. And then studying a memoir, how to write a memoir, and be effective with that. So I got some coaching on that and did a lot of research, and then did research for end of life experiences and things like that. So it's not a how to book, it's a what I did book. So people will get some tips, I guess, because I was pretty successful in my approach, the unique approach from a son taking care of his mom. And if nothing else, they'll be entertained because there's a lot of laughs in there, too. A lot of friends have said I laugh and cry, sometimes at the same place, but it's a fun, entertaining book as well.

[00:16:09.110] - Peter

And when you said in terms of your role as a carer, firstly as a male carer, perhaps it's not as unusual, but he's still probably more unusual and also a male carer of a female parent, that must have posed some interesting things about it as well.

[00:16:30.750] - Mark

Yeah. When you first see, at that point, my mom turned 90 when I was taking over. Yeah. So you're seeing your 90 year old mother naked for the first time and you see what age has done to her. And she had open heart surgery years before, and now she has a pacemaker in her chest. And, yeah, it was a little shocking, but I assumed the role of the caregiver. So you got to get over it and get on with it because I had a job to do. Maybe the acting experience came in very handy because I was able to say, okay, this is the new role. I'm a caregiver. I'll deal with the son later. But it still is your mother. You have to keep that in mind. And there was no lines that we did not cross because with hospice, I learned everything. How to take care of bed sores, how to take care of things that weren't coming out of the body when they were supposed to or on whom and stuff like that. So it was quite an adjustment. Again, it was like a first time parent. So I learned on the fly and we did pretty good.

[00:17:44.950] - Mark

But there were some times I made some mistakes or I got a little angry. Not at my mother, so to speak, but I got angry at the situation with the frustration. So my mother never swore. My father didn't either. They were very good people. They said funny words instead. But I did swear, and I still do. I have a couple of favorite words anyway. So when I got frustrated, I would swear and my mother would get upset and I would apologize and say, listen, I'm sorry, but this parenting thing is hard. And she says, I guess, but I never swore. And this was a mother of six. So I said, okay, I got it. She was very good at guilt tripping, so I had to be very careful because I didn't want to upset her too much. So I've got pretty good control over the words when I need to.

[00:18:54.010] - Peter

My guest this week is Mark Steven Porro, and we're talking about "A Cup of Tea on the Commode," which is available via all major booksellers.

[00:19:02.820] - Peter

Yeah, I mean, did you feel a close relationship, come with your mom and maybe share things and know things that you didn't know about?

[00:19:14.770] - Mark

Yeah. Well, what was funny is, all right, so she has six kids. I'm the only one who is caring for her 24/7 which includes wiping her butt. She did have some bouts of dementia, and later on, a doctor did test her and said she has a bit of Alzheimer's. And so one morning she greeted me with a big smile and she says,

and what is it I call you? And I thought she was joking because she had a pretty good sense of humor. And I said, are you kidding? And she says, no. And I said, name your children. And she named everybody Laurel, Michael, Carol, David, Deecy, and. And she had no clue. So I said, I'm Mark. And she goes, oh, Mark. Mark with a k? So she still didn't make the connection that I'm her son. I said, yes, mark with a k, your favorite son. And she says, I don't have favorites. I said, well, you have a favorite to forget. So to get over this emotional punch to the gut, I printed my name, M-A-R-K on big block letters, and taped it to the ceiling, because normally when I would greet her in the morning, she'd be laying in bed.

[00:20:35.210] - Mark

So it started to become a game. It worked out very well. But I would come in in the morning and say, good morning, and she'd say hi, and then her eyes would shoot up to the ceiling and then say, mark. And she was so happy and proud. So it worked out quite well. And then eventually she got to know who I was. So there was very little of that. But she had a lot of interesting visions early on. Most were pleasant, which was good. But she had a parade of children she saw all the time outside her bedroom window. This was the one that she saw the most frequently. And it was a parade of school children about, I guess, eight years old, boys and girls, marching down our street. We grew up on a cul-de-sac, and they were marching around the cul-de-sac and they would stop by her window and wave. And they were carrying. I mean, she gave such good detail. They had white, frilly dresses. The girls and the boys were in starch shirts with ties and shiny shoes, and the boys carried balloons and the girls carried flowers.

[00:21:40.310] - Mark

And it was fascinating the first time I heard this, and then I got a little worried because you don't know if that's someone, an old relative or something calling, saying, come cross over. And so I said, any relatives? And she says, no. And I said, do you know any of them? And she says, not sure. And I said, are any asking you to join them? And she said, maybe. And I said, come on. And she said, no. So I felt a little better about that. But she had other ones where there were kids on the ceiling, and you have to roll with the punches. I mean, they were fun. So she says, oh, look at all the chocolate coats on the ceiling. I said, chocolate coats? Are they chocolate colored or are they made of chocolate? She says, chocolate colored, silly. I said, you're seeing kids with chocolate coats on the ceiling, and I'm being silly. So we would have fun little conversations about these things. But it was fascinating because we're going to go through this, I think, at some point. And so if you face it, I guess, with certainly an open mind and definitely an open heart, it makes it much better.

[00:22:59.420] - Mark

There's no judging or anything like that. It's like, hey, this is the way it is. And it was good. And so I wanted to make sure that other people knew this, and especially family members, because they wanted to learn about their mom and their grandmother and some of the stories. Maybe I went a little too far because I wanted this to be an honest and open book. So there's a lot of people who have read it go,

wow, I know you much better than I thought. So I take that as a compliment. That's a good thing, though some of my family members might go, you shared a little too much there.

[00:23:41.110] - Peter

Yeah, I think you should. And I think it's a very brave thing because a lot of people would find it difficult to portray all those things that you went through. It's the good, the bad and the ugly, isn't it? Basically, in everything you've gone through as a carer, he's still pretty brave to put all that out there for people to read in a book.

[00:24:03.790] - Mark

Yeah, well, it was a good experience and an important experience, and I think people hopefully will get something out of it. What was interesting about the most difficult part about writing the story was the structuring it to make it, I guess, fun and interesting for outside of other readers. And so I have a lot of flashbacks. I go through somewhat chronologically my experience. It was a three and a half year journey, but I have earlier scenes in life that helped inform those current situations, because the way I was brought up or some of my own experiences that I had in my own adult life, and it all kind of makes sense. But, yeah, if you read a certain chapter and then you go, okay, so the previous chapter makes that a little more clear why he did that and stuff like that, that was the most difficult part for me. But once you open that door of stories, I have a pretty good memory. I have a couple of vivid memories from two years old. Once you spark, let's say, one memory that would open the door to other ones. So there were plenty. That's why I say, well, okay, this is a good memory and something.

[00:25:32.880] - Mark

I think it's important, but it may not be right for this book. So that may go into another book. And so I certainly kept those for future use.

[00:25:48.190] - Peter

Sure. What's the general reaction been? I mean, I read a lovely review, which had a really nice line in it, said this book was like sitting down at the kitchen table and sharing troubles with an old friend, which I thought was a lovely sentence. What's the general feeling about the book been?

[00:26:06.950] - Mark

Yeah, I think most of them have been like that. It's very humbling because you never know. And again, you put your heart and soul into something and you don't know how people are going to react. I knew it was good. I knew it was good. When I found a publisher that liked it, they said, we like your voice. And they said the same thing. It's very conversational. The topic is certainly universal and very timely. And so they were very excited about that, but you don't know until you put it out in the public. So most people have had very good, had. Again, the laughs are very important, but there's the tears, too. I had one friend

who just lost her father about a month earlier, and she said, mark, I'd love to support you and get the book, but it's just way too soon. And I said, absolutely. There's no rush. Please take care of yourself. Well, about a month later, she was flying from LA back to New York, where she was originally from, for a holiday, and she took the book and she, on Facebook, did updates of I'm on this chapter and I'm so glad I'm reading this.

[00:27:25.070] - Mark

I'm laughing and crying at the same time. But I love this book. And it was lovely because that was very soon. And she said she wanted two other copies because her brother and her sister were the main caregivers for her father. And so she said it was important for her to get copies to them. And then the sister who read it, who I don't know, also wrote a beautiful review, and now she's a friend on Facebook and stuff like that. So it's nice that it touches certain people. And then there's people from my hometown who I haven't been in touch with for probably 50 years who are finding out about the book because there's a lot of stories about that town, and it took place in that town, most of it, and they're getting a lot out of it and enjoying reminiscing about what was going on in our village way back when and stuff like that. It's been very nice. And then people who've just found the book and what they say, they relate to it, they either went through the same situation, so they wanted to hear a different perspective, or they're going to be going through this.

[00:28:39.130] - Mark

They say that by, I think 2046 is going to be, no, by 2050, I think 426,000,000 people over 80 years old in the world. So this could be a health crisis unless we start taking care of our family members and stuff like that. So I think it's definitely timely, and especially with the baby boomers, we're going to have to deal with this. Fortunately, I've done it, and so I'm hoping that my story will help other people either get through it or learn from it. If nothing else, laugh at a situation where you want to cry. Laughing is good. If that doesn't work, there's always red wine. I suggest that in parenting, wine is key.

[00:29:32.070] - Peter

UK health radio, the station that makes you feel good. I'm chatting to mark Stephen Poro about his book a Cup of tea on the Gamode, which tells his story as a primary carer for his mother.

[00:29:51.270] - Peter

When I started doing this radio show four years ago, I was very, very, oh, should we be mentioning humor here? We're dealing with dark subjects and whatever, but the more I've realized, and I have a lot of friends who are living with dementia, and your humor is absolutely gay for them. And I think it's refreshing what you've said, what you've done in the book, because I think it's so important that we still have the ability to laugh.

[00:30:19.110] - Mark

Yeah. In a couple of years in, we get a call from a doctor who makes house calls, which is very rare in the states. It's down to, like, maybe 1% of doctors do this, but this particular lady said she just lost a patient, so she had opening and she heard about me and my mom. So I said, great. Yes, please come in, because I've played a doctor on tv several times, but it would be nice to have a real one, though. Mom was doing great, and when she checked her out, she said, yes, she's doing great. And at that point, my mom was pretty much off meds completely before she shut down. She was probably on a dozen medications as we all get in, at least in the American system. They say, yeah, just add some more. Add some more. Well, she went completely off meds and was doing fine. And then we added digoxin because of her heart and with her pacemaker. So we had to make sure that her heart was good, and that was it. So this doctor came in and got to know my mom pretty well. And then one day she whispered, I think your mother has Alzheimer's.

[00:31:33.150] - Mark

And I said, I don't think she has. I mean, she forgets my name once in a while, but she remembers how to cheat at cards, and she knows how to steal my coffee ice cream. So I don't think that's Alzheimer's. But the doctor insisted on doing some cognitive test. So she did the tests, and I thought, mom did great. There's the short term memory test, which was the only one she didn't do so good at, but she had to draw a clock and put the hands where the time was. Draw backwards, count backwards from seven, from 100. And I thought she did really well. But the doctor said, no, I think I'm right. Your mother has Alzheimer's. So I turned to my mom and said, mom, you don't have Alzheimer's, do you? And she says, I don't remember. So I thought that was just great. So I'm not sure if she knew what she was doing, but I said, that's priceless. That is absolutely priceless. Help me forgive her for forgetting my name. I'll say, okay, it must be Alzheimer's.

[00:32:38.450] - Peter

It's moments like that, isn't it, that are so really important. And I think time's running out on us a little bit. But the important thing about the book also is the kind of byline of your book, which is basically the message is, I've gone through all this, and I came out the other end, which I think is so important for those people who, as you've said earlier in a conversation, may be going through it, may be about to go through it, but, hey, this is me. I got through it.

[00:33:07.240] - Mark

Yeah. And again, the humor is a big deal, but also empathy. I'd say the biggest lesson was empathy, because you have to put yourself in their shoes, or as I say with my mom, it was in her non slip safety socks because she never wore shoes again. And they're still your mother, but they are still a person who wants to be loved. I found out with my mom that wanting to feel pretty does not end at 90 years old. So I created a thing I called "Day of Beauty," where once a week I gave her the beauty salon treatment at home. And she loved it. And the first time that I did it, I just did it because I thought it would be a good

thing to do and something special. I wheeled her from the bedroom into the kitchen and I stopped in front of the dining room mirror. And she is stunned because I don't know the last time she looked in the mirror, first of all, and I don't know the last time she looked in the mirror and liked what she saw, but she liked what she saw. And I leaned in and I said, who is that pretty girl?

[00:34:18.500] - Mark

And she just beamed. And it was lovely. And I just said, just the power of a small gesture like that made her feel great, but certainly made me feel great, too. So those little things that you can do are important not only for your loved one, but for yourself. And so it was much easier for me to say goodbye because I don't think we left a conversation uncompleted. I had absolutely no regrets. And she died, I think, the way anybody would envy, in her bed, surrounded by love. And luckily for her, fortunate, and I think for my dad as well, in very little pain. But they were in their beds in their homes. I was with both of them when they took their last breaths. And it's a surreal moment and very touching, but I wouldn't have had it any other way. It was a beautiful experience, certainly for me, but it made me very proud that I was able to do that for my mom.

[00:35:28.650] - Peter

Well, I think that's a really nice place to leave it. Mark, the book, "A Cup of Tea on the Commode" is available, and I'd urge our listeners to look it up. Thanks so much for being my guest here on the D word. I've really enjoyed it.

[00:35:47.140] - Mark

Oh, thanks, Pete. It was a lot of fun.

[00:36:00.690] - Peter

Thanks to Mark, the book is not only a great story, but it's also an excellent read. It's available at all major booksellers. And there's more at the website acupofteaonthecommode.org. That's all for this week. Thanks as always to Angela, my production assistant. Next week I'm going to be talking about the use of music therapy on mental health wards with my guest Naomi Thompson from Anglia Ruskin University. So until then, thanks for listening and take care.