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Pillow, pills, poop, piss, and pain

Episode Intro

- Blood, sweat, tears shared by two.
- Helping one end and another begin.
- A disaster that ultimately gives back.
- Hearts clubbed by diamonds in spades.
- We learned, we cried, we continued.

Denise Brown of caregiving.com asked caregivers for their 6-word story about caregiving. Brilliant!

00:46 Podcast Intro

Welcome to health hats empowering people as they travel together towards best health. I'm Danny van Leeuwen. I have worn many hats in my 40 plus years [00:01:00] in healthcare as a patient, caregiver, nurse, informaticist and leader. Everyone wears many hats, but I wear them all at once. We will listen and learn about what it takes to adjust

Welcome to Men Caregivers, Part 2, the Panel. Part 1 was interviews with the panel, Ben Carter, Patrick Egan, Jolyon Hallows, and yours truly. All at the National Caregiving Conference in Chicago in November 2018.

Here are some of our 6-word stories:

- We did it because we could
- Pillows, pills, poop, piss, and pain
- 20 years a caregiver. I adapted.
- Key word isn't 'men', it's 'caregiving'
- Personal care? It depends? Mother, wife?
- Managing the Dis Ease of Disease

Introductions

02:09 We did it because we could

Jalyon Hallows was the primary caregiver for his wife Sandra who had Parkinson's Disease. For over 20 years he cared for her as the disease progressed. He has recently published a book on their life together. His book, a *Parkinson's Life, and a Caregiver's Roadmap* is part memoir and part how-to guide for caregivers. **Patrick** lives in Boulder Colorado with his husband and a dog named Molly. He's the caregiver for his parents who live in a senior community nearby. He has a passion for using technology in a way that enhances and adds fun to the caregiver experience. Bottom line, he likes to use humor and empathy to help others transition from technical overwhelm to using Tech that cares both for the caregiver and the caree. **Danny**, an action catalyst empowering

people as they travel together towards best health wears many hats in healthcare. He's a patient with multiple sclerosis, has been care partner for several family members' end of life journeys, a nurse for 40 years, and an informaticist and QI leader. Danny blogs weekly at Health-hats.com. **Ben Carter** is a professionally trained life coach speaker and corporate instructor who believes that all experiences whether opposition or opportunity are life lessons. Ben incorporates his personal and professional experience to inspire individuals to acknowledge life problems by solving them with life purpose. Ben believes in the power of motivating and inspiring everyone to achieve excellence in their lives beyond the challenges that they may face by using their inherent skills gifts and talents. So, help me welcome the men's male perspective panel.

[Jolyon Hallows](#)

Welcome everyone. This is not really a moderated panel, because we couldn't agree among us who was going to be the moderator. Nobody wanted the job. But do you guys want to say more about yourselves or okay. Okay. Why do we begin Ben? Why don't we begin with you?

[Ben Carter](#)

[04:21 90-day caregiving experience with Mommy](#)

So, to give you a little bit of insight on what that looked like for me. First, Danny and I were kind of talking about this yesterday. The male perspective on caregiving. One, I didn't know that I was a caregiver and two, I didn't know that there was a male perspective to have. I cared for my mom and I call it the *90-day caregiving experience* from the time my mom's diabetes and her experience with prescription drugs all escalated and elevated to the point of heart attack and stroke, coma, experience with mental health. To her unfortunate transition in a 90-day period. And so, for me what may have been a three-year, five-year, ten-year experience for some, literally all happened in 90 days. And so, when there was something happening every single day for 90 days straight up to the point that we buried her. That was my experience and I had never dealt with anything before and I talked about this a little bit in my talk yesterday. From managing her finances to what her version of an estate was. My mom wasn't married. I'm the eldest child. So, I was responsible for having the conversation around living will, DNR, conversations with her primary care physician. Fighting them on trying to identify why she was prescribed 9262 meds and why were they all ineffective? And ultimately the one sitting at the head of the table making all the funeral arrangements. And so, it was quite emotional and life-changing. I didn't realize until after my mom had transitioned that I was in fact a caregiver. And I had all of this great information and knowledge to share. I think we all do. That's what led me here. The opportunity to kind

of talk about that experience and what it felt like and how I was able to move past and through that. So yeah, that's me Danny you're up.

Health Hats

06:46 Pillows, pills, poop, piss, and pain

Hi. So, I'm a nurse. I've been a nurse for 45 years. My first caregiving experience really was with my mother as a child. She was an unhappy person, a holocaust survivor and spent a lot of time in bed as I was growing up. and I didn't know that I was a caregiver either. But I was bringing her meals and doing her bidding. My first real labeled caregiving experience was with my grandmother who was also a holocaust survivor and not that happy of a person. She was failing and living in a nursing home in San Diego and we were living in West Virginia at the time. So, we added on to the house and brought her home and she lived with us until she died. And our kids were young. It was a really difficult experience because she was so unhappy. It really pushed my buttons that she was so unhappy. During it I felt a lot like a failure because she was so miserable. Now that I'm older and wiser, I realize it had nothing to do with me. Some years later one of my sons had a melanoma and in the period of about 18 months, maybe two years. He had the basic cut it out, and nodes, and chemo, and then brain tumors, lung tumor, death. Our caregiving was very different. Grandmother and son are different animals in terms of caregiving. And actually, caregiving with my son was a really uplifting experience. He was of the "I wasn't born with a tattoo on my ass telling me how long I had to live" variety of person. So, there was actually a lot of humor in the tragedy. And then, more recently, my mother died. The thing that was different was that in her last six months of life, she found her humor muscle, which I had actually never seen before. So that was sort of a hoot. But it was long distance caregiving. She lived in San Diego. We lived in Boston. I remember the phone call I got it two in the morning. My mother saying, "Oh this dying shit. It's so boring. It's just the four P's."

"What do you mean ma?"

"Pillow, pills, poop, and piss."

I'm a nurse and I have a problem when people talk about male nurses and how different male nurses are. Because my experience is that there's the same variation in characteristics of people who are nurses whether they're men or whether they're women. And there is a much larger proportion of men who are caregivers than there are men who are nurses. I've been a nurse for 45 years and there are still only single digit percentages of men who are nurses but with caregiving it's around 40%. So that's a very different proportion. And again, there's every stripe of person as a nurse and every

stripe of person as a caregiver. I can't say that being a nurse has helped me be a caregiver. Because it is just so different when it's yours. In a way I think being a nurse has been a hindrance. Because I'm pretty full of myself: I'm a nurse and I just know all of this stuff and just, not so much,

Patrick Egan

10:47 Caregiving stronger with a diverse community

Good morning. My name is Pat Egan. What an act to follow. But one thing that you said that stuck out to me was we're all different stripes. And I think that's true. My background is having been mostly in training in Corporate America. Then training for a long period of time for the medical company, Medtronic. Last year I was in Chicago wasn't planning to come to this conference but came because I was in town for something else. I had read about it online. I really had liked the caregiving.com website and so was just blown away when I came last year about how quote-unquote un-corporate and un-sales oriented this conference was. In the fact that it was mostly lived experience and people were coming here to share their personal stories, their journeys, of how they had become caregivers. How they're struggling with it today, and what they're thinking about for the future. It really touched my heart. I used to do training. I really like doing technology, working with technology. And I am a caregiver. I care for my parents. They live two blocks from my partner and me. My step dad, who's not here this week, has Parkinson's, early Parkinson's, but is slowly deteriorating. And my parents live in a two-story townhouse. And so one of the things that I have started to do last year was to look at, of course, you're always look at options, or maybe you look at Assisted Living. Might there be an easier way to structure your day-to-day life. and they were adamant that no they want to stay there. They want to live age in place as long as they can, as long as it's healthy. And so, I started to do some work about well, what services, what products are out there that can help people stay in place? I have two sisters live in Colorado, Boulder, Colorado. I have one sister in Alaska and I have the other sister in Minnesota. And so, my parents were trying to decide which of the kids were they going to move by I think I was the warmest of the three locations. Being in Colorado because sometimes I think there's an assumption that the daughter would be the one that would care for the parents. And in this case, it was the son, me, and I love it. I've learned a lot through it. Again, I was very touched by the community that I met last year. And one thread, you know, when we got together and talked on the phone prior to this panel on one hand, there's the argument that caregiving is caregiving, male or female, most of the actions of that are similar. But on the other hand, there is a difference with men caregiving in that there aren't as many of them, visible anyway. And

when you go to a conference like this or other ones, other environments that you go to. I've gone to some Area Agency on Aging programs in Boulder is really predominantly female. And I think one of the reasons why is because what people think men, what are men type roles and what are female type roles? We can talk about that a little bit later. I think the caregiving community is stronger if we have a diverse group in every sense of the word and I think if caregivers can match the makeup of the people they care for it'll make that whole profession stronger, make us better. So that's my background. Thanks.

Jolyon Hallows

13:48 20-years a caregiver. I adapted.

Good morning, everyone. I'm Jolyon Hallows and as the announcer said my wife was diagnosed with Parkinson's Disease. My background is that I'm a former computer geek. She was a nurse. So, we got the caregiver/caree role backwards. If I have to say the advantage of Parkinson's is that it is slow moving. So, I had the option of adjusting and adapting as her disease got worse. It's not like Ben. I'm just awed by people who can take on the caregiving role in an instant. It took me 20 years to adapt to it. I'm a slow learner. But when she was first diagnosed, she didn't need a lot of help. Okay, sometimes help getting up from a chair or when we went walking, I was noticing that when she held my hand, it was more and more for support rather than just affection. But the disease is progressive. And as she declined so I became it gradually dawned on me that okay, I guess I'm a caregiver. She passed away about a year and a half ago from complications from the disease. I learned a lot about caregiving in looking after her and it seemed to shame to let it all go to waste. So, I have written this book. It's called a "Parkinson's Life and the Caregivers Roadmap." That's the sales pitch. And I still haven't clarified exactly how I want to do this, but I do want to convey to caregivers how to do it. Because when it when it hits us, we're all novices. We have no idea what to do. And as Danny said even if you're a professional it's vastly different being a caregiver because there's so much more than just the mechanics of your profession. When we talk about men as caregivers, again as Pat said, caregiving is caregiving. If you need to give somebody a bed bath or you know help transfer people. It doesn't matter. I guess men do have a slight advantage over women and if in that I my wife was slight, so I could transfer her easily had our positions been reversed. She would have had a problem, but that's a physical difference that doesn't always apply. In terms of the psychological difference, I suspect that men think of themselves as think of women more as carers and men more is providers, but I don't know that that's a barrier to caregiving. We have some statistics on caregiving, men as caregivers.

Patrick Egan

16:40 Statistics about Men Caregivers: The numbers

When Denise asked us to put this panel together and one of the things I thought I would do is do a little bit of research through our brother organizations about what is the prevalence of men and caregiving and how might that be changing over time. So, here's some information they had from November 2017 in the AARP Bulletin. Roughly in the US 16 million men provide care. Forty percent of caregivers for people over 18 are men, which is pretty amazing, and a lot of times men don't self-identify as caregivers. In fact that word and I think that's one of the benefits of a program like this is we're starting to create a language a lot of people do care giving but it's not called that. It's called doing the bills for Mom and Dad or helping out or making sure that they've got care or they've got someone to come and help clean the house. But those are all caregiving activities. 25% help with feeding and or bathing, 29% with dressing, 30% with a bathroom. I think with these three things you can see where there may be some populations men that are being cared for that would prefer to have a male caregiver for some of those kinds of activities. And over 50% perform nursing and or medical duties all the way from professional nursing down to just med management and administration. So, everything inbetween. I think one of the statistics that jumps out about this is just that this is a population that is there and has been there for a long period of time that's starting to get called out in a different way. And that's one of the opportunities we have with this caregiving conference is to share our experiences of being caregivers and also being men and even within that group it's a diverse group as well. Four questions. Well, the other thing I'm just going to put up the other issue that we all grappled with when we were on the phone are these four questions. I won't go through each one of them because we're hoping to get some questions from you as well and to answer questions that you would have. I'll start with the first one and then we can just share a little bit and again, hopefully get questions from you. What are the biggest challenges for men as caregivers? Any thoughts?

Ben Carter

18:47 Welcome the new VP of Caregiving

I think the challenge would be again the label of male caregiver and what the perception or the expectation is. For a lot of us our caregiving experience is very intimate because it's a family member to son or Mom or wife or Dad. And we're not assuming a new position. Right? So, it's not a job description where they go here, you're now the new VP of Caregiving for Mom and these are the 12 things you need to do daily. You just assume the responsibility based on the need. I think what the challenge

is. This could be for anyone. I'm a male so I might say it's a male challenge. Is dealing with someone on the outside who has an expectation of who I should be and what that should look like. If I go into the room and my mom's last name is my last name. Is this your wife that you're making this decision for? Where's her husband? No, there's no husband. She's not my wife. Yeah, she's very young and she's my mom and I need to make this choice. I need to see the social worker. When you deal with the outside, some challenge of what people expect in terms of your role in your careers' life. But for me, like I said, at the time I didn't it wasn't about being male or any of those things. It was just me being me. I was just being the son. I think sometimes the expectation is that men are going to be a little bit more brute and aarrhh, make it happen, and get it done. And that wasn't the case. I know my experience inside of my family is because it was really only the three of us. It's me, my sister, and my mom. My sister did a lot of the work and traditionally they were good friends, right? So, it was mom and daughter and they had that relationship but the difference was my sister said, "she listens to you." So, it might be that thing, where mom might be willing to hear more from Son than she will Daughter because Daughter, you're my friend, you know, you're like my girlfriend. And when I get upset with you, I could tell you to shut up and be quiet. Where with me and my mom it wasn't always that kind of thing. She'd lean in a little bit more and say well, what do you have to say? You know, what's your take on this but that was inside the family and that's the family dynamic. I'm sure everybody has that dynamic where between you and your two sisters, your parents might be willing to hear something differently from a sister based on their personality and their role. But my challenge wasn't having to do anything with male. It was just the expectation of who you are. What's your role in this person's life? And do you have access to this and can you provide that I think that was my major experience its.

Health Hats

22:05 My advice: Take care of yourselves

I would echo that. I used to try to give advice to high school boys who were thinking about their career and trying to interest them in becoming nurses. I have to say I failed. I failed pretty miserably. No interest. On the other hand. I feel like the advice I would give some, anybody getting into caregiving, you know sort of the same - accept help. Set it up so you can take a break once in a while. How are you going to take care of yourself? Do you take a walk every day? It's tailored to the person. I've met caregivers who are pretty bottled up people. I can't say that it's a gender specific thing. And if you haven't figured out about me yet, I'm an extrovert and I wear my shit on my sleeve. So, that works for me. But everybody's not like that. You meet people who are working hard as a

caregiver and they don't. Well the advice for a man or a woman who are bottled up is: there's stress you can manage and there's stress you can't. Being a caregiver, well, you bought into it and so, there's the stress. But being bottled up is something you can do something about so, you know, it's probably worth doing something about it. So, I don't know because I don't know. It's like I don't think any of us are the right people to talk about really. What's the difference I would be really interested to hear if anybody here has like strong feelings or understandings of a difference or you know would answer any of these questions cuz I don't think you're going to get from any of us. This is male.

Patrick Egan

Thank you.

Attendee

24:09 Male panel? Or highlight other diversities?

On the dais and sharing with us your perspectives. This is my second year at a Caregiving Conference here in Chicago. In each of the two years I've come to hear this panel, the male perspective because the subject has been on each year's agenda. I came again this year because I wanted to hear what you see is different. What I hear, what I heard last year, when I hear again, this year are the same things I would say sitting up there as a woman. We have such common stories. When it's about family, it's about the emotional baggage. It's not about gender, I don't think. And so, I'm really curious about why any of us feel we need this on the agenda or whether we ought to have diverse panels with all of us talking about our personal experience.

Patrick Egan

25:08 Key word isn't 'men', it's 'caregiving'

I think that's a good question and. You know, I wondered the same thing when I saw I'm going to be on the men's caregiver panel. Would you like to be? I had to think about it. Wasn't an automatic yes. My background's in technology and I was planning to talk about that. But the reason that I do think there's a role for it. I'm looking at, not just our individual lived experience, but at society as a whole. And again, I mentioned I was in HR. When you look at the background, the helping professions, whether it be nursing or childcare or those kinds of caring and supportive type professions ones where you have to provide empathy, etc are often not paid the same as other similar work. The teaching in general is although lots of men and really powerful men are in. Teaching as a profession it's not as rewarded societally. And I wondered, just wondered, I'm not sure I have all the answers to that as a caregiver. Was that viewed as 'less than' in some way.

And so, I do think there's power in language and making sure that everyone is represented. But I concur with your statement a hundred percent. We're much more alike than different. Men in caregiving: the keyword there isn't 'Men' it's 'caregiving'. And that's the key word that we have across the board. If there's anything kind of tacking on to what Ben said that's different for men is the assumptions when we go in to help is that sometimes we literally have to say, I'm providing care for this person and make it explicit because the assumptions are that this is the one who's driving them or this is the one who's paying the bills. And they don't necessarily assume that this is the one who's helping them at home and providing supportive and nurturing care. And so, I look at it and certainly as a gay man as well. It kind of frees you up because there aren't the stereotypes of a family is one thing with Mom and Dad and the daughter and the daughter takes care. Once you've accepted that we're diverse and that your biggest caregiver could be someone who's not even related to you. And the more you can get that comfort and that language out there, I think the better we all will be, men and women as caregivers. So, thanks for that question.

Jolyon Hallows

27:10 Not so many men here. Why?

Yeah, I agree. I had trouble with that question the biggest challenges for men because to me caregiving offers such an immense mass of challenges that the proportion that might apply to men is almost insignificant. And yet there's something to it because I look around at conferences like this. This is a panel discussion on the male caregiver, but there are more women in the room than men. And I look around the conference and not just this conference, but any conference on the deals with caregiving and men are about 40% of the caregivers, but if they're ten percent of the attendees, I would be surprised. Now I don't complain about this. I've never complained about being outnumbered by the women, but there's something there's something holding the men back, male caregivers back, from identifying as male caregivers. And it's not that they're not doing the work. It's that somehow, they don't see themselves, either they don't see themselves as caregivers or they don't think they need the help. And I'm not too sure what it is. I don't have an answer to that question. But there is a difference in the attitudes that men bring towards their roles as caregivers.

Ben Carter

28:29 We didn't know we were caregivers

I think to piggyback off of your statement. It's a little bit of both. So, I am a behavioral coach and I'm an independent contractor for a fantastic organization that provides

telehealth. So, what that means is you get a fantastic coach, which is me, and you get a therapist and you have an opportunity to really take a look at your life as a whole and get therapeutic services. And then you get someone that says okay now that you've taken a look at your life and we are in present-day, how do you want to move forward? And we interview our perspective participants. There's a story about a particular client that I had who was a caregiver but didn't know he was a caregiver. He thought that he was joining the program for Stress Management, but really realize that in caring for his mother and his sister I'm just being a good son. I'm just being a good brother. I'm not a caregiver. But he didn't know that until we said okay, this is the program that we have for Stress Management and then we have a program specifically for caregivers and we go through each program. And he's like, "oh, I'm a caregiver?" Yeah you go, and you take Mom to dialysis three times a week. Then you take your sister to her doctor's appointments. You manage mom's bills. Yeah, you are a caregiver. And it's because you're in that role that's elevating your stress and he's like, "oh, I was just doing it. You know I was just in it. I was the doing you know, I wasn't necessarily knowing I was the be. I was a as a caregiver."

30:27 [We learned, we cried, we continued](#)

So, I think what happens with society and I think maybe the real reason we're here is society doesn't always give men permission to have a range of emotions and that means we don't always have the opportunity to lean in as nurturers. And caregiving is so invisibly associated with nurturing and when we think about nurturing holding, soft, warm, we don't always think about men in that role. And so, as someone who was - now I realize it like my clients - I was a caregiver and someone who supports caregiving. You almost have to give men and little boys permission to lean in emotionally and feel what you're feeling outside of stress and anger and rage. Because Society gives us permission to be mad. Men can be mad and that's acceptable, right. But we don't necessarily have the permission if I was caring for my sister to just take the sister and hold her close, right? We're almost uncomfortable with that. We don't we don't want to see it. So, when dealing with my mom. There were moments when I had to identify how I want it to show up. And so, yesterday in my talk there were moments when I said I was the parent and I would say "go to your room. Just go to your room. That's not acceptable. We're not going to do that" Right? And then we would laugh about it because she would say, "okay you're going too far" and then there were moments when I had to say, "it's okay. Mommy let's just let's just break" And we would cry. Let's just let our hearts break and let's be in this moment. I think as caregivers when you're caring for a son, parents, especially a spouse right? That's your partner that your lifeline. I think that sometimes based on my experience, the world says be the husband, lift her up, put her in bed. But

is it appropriate for you at two o'clock in the afternoon when she's not responding the way you would like for her to respond to sit next to her and just cry? And have that moment and hold her hand and maybe wipe your tears with her hand and that be a part of the process. I don't know if we've been given that permission. And so, I think that's the real reason why we're here. Because, when you think about caregiving and the role of what men are allowed to do and who they're allowed to be. Cut the check. Walk away. And let the chips fall where they may. We don't have the opportunity to kind of lean in and experience the range of emotions. So that's why we're really here. To say, "yeah, we traditionally especially in our culture women get to healthily fall apart and put themselves back together again." What does that look like for a male? And hell, what does that look like for a male caregiver? Then you're weak and you can't take care of your caree. That's why we're here I believe.

Attendee

33:41 [Personal care? It depends? Mother, wife?](#)

So, a couple of challenges I see. I was 17-year-old when my mom passed away of cancer and the challenge I had was like hygiene. She didn't want me anywhere near her in the bathroom. So, that's the big challenge. Another challenge I see now is. So as a 17-year-old my mom passed away of cancer. And the hygiene thing was a challenge for me. She didn't want any part of me in the shower with her helping her to make sure that she didn't fall. So that's the number one challenge today. I see men the spouses some of them it's their wives so they can handle it but there are other husbands that when their wives just take on a different personality, they just morph into some Rambo or something. They just don't know what to do. They just stare at them and say "Mike, I don't know what to do." And that's a big challenge for these guys we get a man cold and we're out of commission for two months. And their wives get a cold and they have to still do everything that they've been doing. So in that particular aspect, I see that as a big challenge for those men that just they don't have any experience and their wives all of a sudden go down, you know, they start declining with the dementia and they get angry at their husband for no reason, but you mentioned it before you got to sit with them for 15 or 20 minutes and they'll get through it. But these guys don't know that. So those are two challenges that I see. Thank you.

Ben Carter

35:06 [Managing the Dis Ease of disease](#)

Are we responding to that do you want us to respond to that? I think so, I think again it goes back to and geesh. I mean, we can't change the world, but I think that is how we

were raised in this culture is to not know what to do. Until you mentioned the man cold and I don't know if any if anybody else is this way, any other male is this way? If I get sick, I do shut the world down. I'm sick and I can't do anything. Whereas I have a sister and we're very close in age and she gets sick and she's like, yeah, I had 18,000 meetings today. I took my daughter to gymnastic dance and the doctor says a hundred, I have a hundred-twenty-five-degree fever and I'm like. What do you mean? I only I oh, okay. Well, maybe I will get up and you know take a shower. I think it's our society and I think as men we have to start having real conversations and saying. "dude, you can do this. Stay in the moment. Feel what you're feeling. I know you feel like you don't know what you're doing." And that's true because you've never had to do it before. Understand that this is not your wife responding to you. This is the Dis Ease of the disease. That's dementia.

36:30 Mindfulness. Be in the moment. Deeper.

And now your role is to be able to in a moment. You've got to use your Superman power. You have to be able to look at your wife and go, "Oh, that's dementia." That's what showing up now and really be in the moment again. We've not been taught to be in the moment. That's why this is so important in the whole concept of mindfulness. And so, you'll you traditionally speaking. I'm being very stereotypical right now when I say especially depending on where you are in the country. Mindfulness to a male- that's all philosophical fluff. That doesn't mean anything, but mindfulness is kind of shut up your thoughts and be in the moment. And being able to identify my wife is having a moment of clarity. Let me enjoy that versus she's not. You know and her Dis Ease is showing up and that's what's running the show. How do I respond to that? And if we're responding to the Dis Ease with our own dis ease and uncomfortableness of, I'm afraid because that's not my wife or I'm annoyed because she's behaving in a way that she doesn't normally. That's not her cognitively. And a part of what we're responsible for doing is being educated. Google is your friend, you know, your phone is not just there for you to play Solitaire and take pictures. The more information, you know about Parkinson's, about Alzheimer's, about my mother was diabetic. My mother also had as many of us are dealing with an issue with prescription drugs that we didn't know existed until after she was severely ill. The more you know, every time you fill a prescription research what you are refilling so that you know, oh that's a side effect of the fourth prescription that they're taking. We have to be held accountable for being in the know and aware of what we're experiencing to not enough to just say. Oh, she's sick. And she's upset with me today. That's not what it is, Buddy. Go deeper and as men we have to go deeper. We have to kind of disassemble this thought process, and this myth that we don't have a range of emotions. Say, "I don't know what to do", ask for help, and then do something

about it. That's just the you have to dig in, you have to lean in, you have to be accountable, you have to be responsible. Men don't read the directions. We just want to put things together. We just want to fix things. This doesn't work when you are a caregiver. You have to read the directions. You have to do things step by step. So, encourage the men in your life. If you are supporting caregivers' male caregivers, encourage them to see things a different way and see new possibilities. And so even if you have to sit with them and say, "what are your thoughts about this? What's your process? You can't fix this. You can't. And it's not broken. There's nothing broken here. This is just the way your life is. There's no fixing." I asked Jolyon this yesterday, "How do you deal with people in resistance?" Right because they don't want it to be. You can't fix it. You can't fix Parkinson's. You just have to be. I don't know if that's the answer you want it but that's the one that you're going to get.

Jolyon Hallows

40:06 [Problem solver can't solve them all](#)

When I was dealing with my wife's Parkinson's. I'm a Problem Solver, that's my background. Give me your problem, I will do my level best to solve it. It might not always work, but that's my orientation. I'm going to solve the problem. And in caregiving there are a lot of problems and I was able to solve them. My wife, I heard a crash in the bathroom one day and she grabbed a hold of the towel rack. And of course, the thing gave way. So, okay, problem. I got a reinforced bring carry my tools and bring out the wall anchors secure the towel racks to the to the wall. Problem solved. But there are all sorts of caregiving that is not solvable. Problems that I just cannot solve. I couldn't solve the Parkinson's. I couldn't solve her tremor. I couldn't solve her stiffness. And to me that was really frustrating. There has to be some way to fix this as you said and there isn't. And it took me a long time to get it through my thick head that okay, somehow, I have to deal with this in a different manner. And that manner meant, as you say, holding her hand and just being with her and wishing things were different.

Patrick Egan

Thank you. Are there any other questions? Okay.

Attendee

41:40 [Backlash against men in nurturing roles](#)

I want to thank you for coming on the panel and I think and I would love for there not to be the need for a gender or gender identification panel at the same time. I've been working with fathers for 25 years. And what I'm discovering is this wonderful expansion

of assumptions about gender and gender roles. So, I've always known that when a father meets their baby. Their heart opens up as much as any other parent, right., But then they're slammed into gender roles and expectations that shut that down. So, to see men that are not holding back from that that are learning to have that language of nurture and to be comfortable with it. And their experience often which is shared with me is that they have people going. "Oh, wow, you're so amazing that you're out taking your child for a walk or your soothing your newborn baby in a in a restaurant and particularly for gay dads as well. It's like the everybody's looking around for where's the mom, right? So, my comment is of gratitude that we're having this conversation. And also, what I've just recently encountered this week is the amount of aggression and trolling that happens. There're some great daddy blogs like Woke Daddy where it's a stay-at-home parent who's talking about his experience and the amount of hostility and hate and push back that he's getting for being a man who's honoring the role of caregiving is getting worse. So here I've seen this progression over these last 25 years. And instead of celebrating that, it's no no, no women's roles, men's roles. Let's make sure that we dishonor anything that has to do with a female-associated roll. So, I just want to you know, invite the question to do you feel that you can be advocates for the honor and integrity of caregiving in a way that uplifts us all. you know, they're sort of that privilege of...

Health Hats

We're here.

Patrick Egan

[44:18 Competing? Caregiver conference run by men](#)

Yeah, we can know we can and thank you. I appreciate that comment. The one thing I'll add just real quickly because I want to get time in for questions too. But I would say if I had been to a traditional, like when I say traditional, corporate type environment. If they had had a caregiving conference, it would be a contest. Who's the best caregiver? Who's the number one caregiver? They would encourage us to compete and we'd have caregiver battles. And that's just how it would be. I think one of the things I really liked and that touched me last year coming here. And again, this year is that this is a supportive cooperative environment. It's such a relief sometimes for men to be in that. We're like, I don't have to win. I don't have to compete. I don't have to be tougher and stronger and when you can let down that barrier and just hear stories from each other. There's a lot of power in that and you know, I'm grateful to this organization and to

Denise for bringing people like that, diverse people together because I think that's how we really do believe. That's how we get stronger questions.

Attendee

45:13 Brothers not caring for mom's hygiene

Well, my challenge is my mom's been in the nursing home now for about I would say about nine years and she now has dementia. She had it before and she's confined to a wheelchair and she has ten kids. She has I'm sorry. She has 10 kids. Most of our kids that live in Chicago and fortunately our males. I hate to say that, but I find them fading in the background. I find them very reluctant to go and see whether or not mom has bedsores. "We can't go there. We can't do that." So, I find this panel is very important because I think you're an anomaly. That's not that many men who get involved. Especially with their mothers when it comes to caregiving. It's really unusual to see it and it's not just me. I know a lot of my friends a lot of people have caregiving situations the men just don't step up to the plate. And the women are the ones who usually doing all the work and it's my challenge is to still love my brothers who don't come in and wash mom's feet or to do things for mom to clean her. Help make sure she's okay and so we can't do that with the sons we can never do that. So, I never get the support I need for my brother's, you know, and it's unfortunate. I wish they were here. But that's my challenge to still love them. Despite their reluctant to help out with Mom. Especially her hygiene issues.

Jolyon Hallows

46:46 Difference between wife and mom as caree

Thank you for that. You've touched on something that I have wondered about. I was caregiver for my wife and I had to give her a shower. Well, we've been married for almost 50 years. So, giving her a shower didn't expose me to anything that I hadn't we hadn't seen for years, right. But I had to wonder suppose I've been looking after my mother. Could I have done the same thing? And I honestly don't know the answer to that question. Because giving a bath to my wife is different than giving a bath to my mother. And I appreciate what you're saying, and I do not know to this day how I would have responded. I like to think that I would have responded well, but I don't know.

Health Hats

47:41 Different abilities. Different willingness. Gender-related?

My sisters would have never given my mother a bath. They just had zero interest. I appreciate that people's abilities are different, and their willingness is different and I'm

sure there's a gender piece of that. I am trying to make the case that it's not about gender and probably I'm a little full of shit. [But should we end on that note?] I mean I appreciate that there's, however many kids and there's one person, doing the work and the others that aren't and, in this case, it's women. And probably in a lot of other cases that's the truth, the same truth. We're messed up.

Ben Carter

48:35 What grandmother wouldn't let me see

I think though to expound on Danny's full of shitness. It may not be a male-female thing. So, your case is very layered. Right? First of all, there's 10 of you and so there's always someone to say "Danny'll do it. Patrick will get to it." Right so we can always put the responsibility off on someone else. What your brothers may be dealing with. Before my mom's my 90-day caregiving experience with my mom. I didn't know for half of my life I was caregiver for my grandmother. So there were three primary figures in my grandmother's life right there was the financial person which was my uncle. There was the physical person that did the physical things behind closed doors. That was an aunt. And then there was the Doer, the errand boy. Which was me now as an errand boy. Because I love my grandmother so much and we had a very close relationship there were things that I would be willing to see and do. So, I would be willing to scream at doctors and I would be willing to stay in the room and see certain procedures, right? So, she knew when to say you got to go you can't see this or they're going to close the curtain. But there were also aspects of her sickness that she kept from me. And so, while I was very hopeful. I'm a planner. I'm a fixer, right. So, I was going to fix my grandmother and I had this plan I had this elaborate plan of what that looked like. And she would be with me, but she had already been told you have X number of days to live. She lived a few more months longer than that.

50:30 Mommy don't die. Can't face it.

I think with your brothers, it's different. Because you're saying it's hygiene. It's not hygiene. It's the finale. It's the finale, right? It's this is it. If I have to wash my mom, then pretty soon I have to bury my mom. And so, if I could just do this and not be a part of that process I could pretend like everything is okay. So, I don't know if it's that they don't want to do it and I'm sure there's parts of it that's like I'm not willing to see my mom's, you know. I had a conversation with a friend and I said one of the craziest conversations I had with my mother was like, "and what's your bra size and I've gotta buy you underwear too?" So, I had to go shop for her. Right? I think your brother's if they have to wash mom then they feel like tomorrow she's not going to be here. And so I think for you, the tool that you're going to have to use is compassion. Because little

boys with their moms, it's a different thing. I don't think it's that they don't want to do it. I think that she's not going to be here.

Wrap up

51:44 [Healing, therapeutic session. Wrap it up](#)

They're telling me, Danny's in my ear asking me do you want to wrap it up? So, we'd like to thank you for coming out this morning. We hope that our individual stories and our attempted answers to your questions provided something that you can use. This was very very therapeutic and healing even for me. So, I hope that you all have the same experience, and I don't know if the guys have anything else to say. I'm done. Thank you. Thank you very much. Thank you very much

Podcast Outro

52:26

- Well, I'm beat. Thanks for joining.
- This was from our open hearts.
- Onward, may the force be with us.
- Honor the caregivers. We need 'em

52:41 [Support my blog and podcast](#)

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