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00:00 Episode Intro

Health Hats: In 1968, the Internal Revenue Service ruled that Charles E Moritz was not entitled to a deduction for expenses for the care of his dependent invalid mother. The IRS ruled the deduction was unavailable because he was a single man who had never married. The deduction was only for women, a widower, or a husband whose wife was incapacitated or institutionalized.

Transcript: Men Caregivers Part 1 #003

Ruth Bader Ginsburg took this case to the Supreme Court and won. **We've come a long way buddies!**

00:39 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 to Life's realities in healthcare's Tower of Babel. **Let's make some sense of all of this.**

01:23 2018 National Caregiving Conference

Denise Brown of caregiving.com invited four men to participate in a panel at the 2018 National Caregiving Conference in Chicago about men as family caregivers. We were Ben Carter, Patrick Egan, Jolyon Hallows, and yours truly. Our personal experiences of caregiving differed widely yet. We were all caregivers because we wanted to, we could, and we did. None of us thought of ourselves as caregivers until after we were caregivers or well after we started. Let me start by introducing Ben Carter who cared for his mom as he describes it in a world wind 90-day blast. His career has been in human resources and now focuses on personal development.

02:17 Ben Carter: First time discovering health was fragile

Health Hats: I asked Ben to tell us about the first time he discovered that health was fragile.

Ben Carter: I don't remember where I was, but I do remember how old I was. I was about six and I was in the hospital. They were putting a cast on my arm because I had broken my wrist. I thought I was the Six Million Dollar Man and so I was attempting to jump into slow motion and doesn't work that way and I landed on my wrist. I was in the hospital at the same time as my grandmother. She was just on a different floor and I really wanted to see her. And I thought this is perfect. She's here. I'm here and they were like, you can't see her. She's really sick. We can't take you from one area to that area. You know for whatever reason I guess germs whatever it was. I don't remember definitively what the reason was, but I just remember like the heartbreak of knowing she is in the same building and I can't get to her and that's when I realized that sick meant the fragility of physical health and emotional health. [Yeah, six.] That's when I felt it. So, I knew that sometimes being sick meant that you have to be separate, you know, and that separate because it's not good for either you or the other person.

03:55 How was it for your son?

Health Hats: Do you have kids?

Ben Carter: I do.

Health Hats: So, how was it for your son when you were taking care of your mom? He didn't I don't think he saw it as me taking care of her. I think he saw it as grandma isn't feeling well and she's living with us for a little while. He was removed from it in that aspect of we're actually

Transcript: Men Caregivers Part 1 #003

taking care of her more than she's just here hanging out. Yeah, so I don't think for him he saw it that way.

04:26 What is the relationship between life coach and caregiver?

Health Hats: Did you set up your life coach business before you took care of your mom or after?

Ben Carter: After

Health Hats: Was there a relationship between...?

Ben Carter: There was definitely a relationship. So, in the final days of my mom being alive, I didn't know that they were the final days. So, we had all of these dreams, hopes, goals, plans, and one of my dreams or goals from my mom was to actually have her become a speaker in some sort of volunteer and women's shelters because she had had an experience with domestic violence and substance abuse and. And I just thought you know, "Mommy you should really - I can't wait until you're better so that you can do this" and you know, she said to me very calmly she said "No, I'm not going to do that." When I go... What do you mean? You've got such a great story. You got to get out there and share it and she's like, "Yeah, no, I'm not going to do that" and I'm like, but what about your story? And she said, "You tell it" and I'm like no, I can't tell your story you're the woman. They have to hear it coming from you. She said "No, you don't have to try to tell it the way that I would." She said, "You were there. So, tell it the way that you saw it you go out and you do that." And I was like bummer, right and I forgot.

Yeah, and I didn't pay her any attention when she said that. I was disappointed but, in my head, I was like, yeah, I'm going to trick her into doing it when she's well fast forward about six months and she had already transitioned, and I was just left with my life. What am I supposed to do with all of this all of this information all of this experience? And I kind of felt this presence that said life coach. I felt it. I kind of heard it in my right ear and I was like, huh life coach that so stupid, right and I didn't really know what it meant for me. I knew what life coaches were because I dig them. I read you know, I love Tony Robbins. Great motivational speakers out there like Les Brown. I love all these people, but it didn't make any sense for me to me. And so, I said no really, you know life. What am I supposed to do? Right and I kind of again like my right ear kind of it - I felt it heat up and it was like life coach. Okay. I still think it's stupid. But how do you become a life coach, so I was in my office and I just turned around and got on my computer and start searching and like nine zillion hits came up and that's how it came to be. I found a place that was literally less than five minutes from my work at the time and I enrolled, and it changed my life.

And that's how I got here the experience of being my mother's son and then being her caregiver and what that meant to me. You know and, in my life, and how I was supposed to not just kind of store that as really good memory but do things like this conference and that's okay.

07:33 What does your son think of your career shift?

Health Hats: So now let's go back to your son. So, how old is your son now?

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Ben Carter: Now he's 18.

Health Hats: What does he think that you had a career shift?

Ben Carter: Yeah. It was a nice transition. So, my corporate career I was a technology instructor. [Okay] so I was a trainer, so I was always speaking. I've always been doing that my entire career and he's been with me. So, I've always taken him to work and so he's always seen me and in some capacity one thing just kind of melts into the other. So it was a great shift in transition. It wasn't like he saw me go from one thing and now it's drastic. It was just very gradual for him. A natural progression is what it looks like for him. So, if you were to ask him, if people ask him, what does he do? What is what does Dad do? He says he's a teacher of some sort. He teaches. It just depends on where he is in the room that day, you know, but he might be teaching about life or he might be teaching about technology or he might be teaching young men. You know, how to become successful, but that's what he would call what I do.

09:01 How does it feel to be a man in caregiving?

Health Hats: I asked Ben how he first reacted when Denise invited him to be on this panel.

Ben Carter: My question was. One, I didn't even know I was a caregiver until after everything was said and done. I didn't know that there was a title or label for what I was doing. I thought I was just being a son and then when she said when the men label or the man label was put on it, I was like, oh that's kind of deep because I really don't know what that means. Because it's not intentional for me to be a caregiver and a male caregiver. And so instead of trying to kind of like decipher it in my brain. I said just share whatever your experience is through the lens of a male. So, I get what she means by that and so share what your experience is and if your experience is. I didn't see it as anything as gender-specific then that's the experience and that's what it's about. I know stereotypically what goes along with the emotional portion of that especially now because I support other caregivers and a lot of them are male, and I know that sometimes they're held hostage to their emotionality and not being able to have a range of emotions based on what they believe, right? And I think that sometimes where that kind of question comes from or panel comes from. So talk to us about being a male caregiver. So, I think that's what that meant. But I really, I was just like, okay, I'll just talk about my experience. I'm not an intentional caregiver, you know, I was just someone showing up. I was just present now.

Health Hats: I'm a nurse. I'm a man in nursing. My view is that there's as much variation in the men in nursing as there is with women in nursing. There's just, ninety percent of them are women and less than ten percent are men, but they're still the same variation in personalities, connectedness and kindness and black and white thinking and whatever characteristics. So my feeling when she invited me to participate in this is I don't want to talk about men because who are we talking about here. What does that mean? Why aren't they like just Universal issues?

11:47 Patrick Egan: First time discovering health was fragile

Health Hats: Here's Patrick Egan. Patrick cares for his parents right now. His parents live together in assisted living near him. His mother has Parkinson's Disease. I also ask Patrick about the first time he discovered that health was fragile.

Patrick Egan: Well, probably I have two younger sisters and one of them had a really serious health scare about four years ago, and she's actually the baby of the family and so she came out of it okay, but at the time she had five children and I remember thinking, if things didn't go well that I just wasn't prepared for that. I had thought of that in relation to my parents or with people that were older. I had not thought of that in relation to somebody that was eight years younger than me. And so, it was a wake-up call that yes, time is precious and you need to take advantage of it to the extent you can every day.

12:51 What is the fun in technology for patients and caregivers?

Health Hats: So, I was reading some of your stuff. And I saw you had written adding fun to caregiving with technology and I was curious about that like the fun and technology. So how [good question] what's that connection?

Patrick Egan: Well, because it didn't start out as fun. I started out and as truly an informal technology resource because my parents and then people that lived in their assisted living community had all kinds of questions about how do you set up a router? And how do you, basically, they would call and say the internet's broken and basically meant their email wasn't working or something of that kind. So, it started out as being kind of problem solving but what I realized that technology could be fun with them because quite often they wanted somebody to come in and fix it whatever the problem was that they were experiencing. And I would come in and I would have them walk me through whatever their situation was and then help them do it. And I would I would literally have to almost sit on my hands and say I'm not going to touch the keyboard, but I want them to do it and it started with the computer and then it turned into I found that actually where I got tons of questions and it was fun was when people wanted to see pictures of their kids for example on some form of social media that either their children or their grandchildren were using. All they wanted to do is be in the loop. They wanted to be connected to it. And if you could find a way to do that, they would laugh. They would kind of come alive. They would really have fun because it wasn't like you have to learn the computer. It was more like I'm going to talk with my niece or I'm going to, see pictures of the new grandchild or something like that.

And so I like that and then the other thing that happened with technology being fun was when all this new speaker technology came out like Alexa or Google Assistant and all of a sudden people that just had absolute phobia about typing and entering a keyboard could do it with talking and it made it made it they started out fun with that. So yes, that's to me. I realized that. A lot of times you've talked about technology and sounds like work. It sounds like drudgery like doing your taxes. And what I would have tried to do with them is what is it? That makes you laugh. What is it that you want to do that makes you smile? And a lot of times technology can

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help people particularly, you know careers that are somewhat housebound or whatever go out into the road without having to leave their house and it really allows them to connect? So, I thought that was fun and you know was able to make it less intimidating and they didn't have to feel like, I'm too old, I can never learn all this. They would just I would say fine, then we'll learn one thing. We'll just learn one thing and get to work. The next time we get together, we'll learn a different one and eventually over time they will call me with things that they'd heard about.

15:44 Buying my mom a cell phone

Health Hats: With my mom. My mom was in San Diego and I was in Boston and I bought her a cell phone.

Patrick Egan: And once you buy them something, you own it from then on everything that happens with that device.

Health Hats: I couldn't get her to turn it on. She would only turn it on when she wanted to make a call.

Patrick Egan: So outgoing only

Health Hats: She wouldn't plug it in and charge it and then she would like call me at all hours. I was not a good help desk to my mother. I was really kind of bitchy

Patrick Egan: because you get frustrated.

Health Hats: I just wasn't the right person. So I said to her why not the next time you go to church, why don't you hire a fifteen-year-old and pay him or her \$15 or ten dollars an hour, something real and let them be your help desk and she did and this that was just a lovely relationship and the person was delighted some young lady was delighted to be making money. And my mother, even though she annoyed me, was a hoot, and so it was like it took it off my plate. she had a lot of fun

Patrick Egan: She made a connection with somebody she would have met otherwise probably

16:56 How did training leaders affect your caregiving?

Health Hats: I also saw looking at your stuff that you're that you do training leaders. I was wondering about like did you take what you knew training leaders into caregiving or did you take what you learned caregiving into training leaders or both?

Patrick Egan: Well the way it worked for me personally was I have what I call my corporate life where I did a lot of training and my backgrounds in Human Resources. So most of the training that I did. I was helping my most popular class I offered was managing the troubled employee. But we would do problem solving. performance management, compensation, interviewing all the basic HR things. When I got into caregiving I well I didn't plan to get into caregiving. It happened with my own family. And so I found that there was a language around, providing care

for people and I realized that a lot of the things that I talk about when managing people really had to do with how in most cases at least for me has been families how they interact with each other when it comes to all you know, we have a problem. We have some people that are on board. Some people are not performing feeling we need to figure out how are we going to work with this person and it's not something you do to them. You have to involve them and their own life. So, I thought there was a lot of crossover between that. But it definitely came from my working life doing formal stand up training and then caregiving kind of happening just it was like a little thing. I did on this side and specifically for me helping people with technology because one thing I learned is when you help one or two people and they live in a community of others, then your name gets out and all of a sudden, you're helping a lot of people do the same thing. And I realize there's really a need for ultimately, they say it's about caregiving. But for technology that it's about learning how to fix something but really to a large extent they just want to be connected to other people. However, you can help them do that with technology for me. Yeah, I think it relates to the same kind of things the same skills that it takes to be good people manager or what it takes to be an efficient and a good caregiver to me.

19:08 Family roles in caregiving

Health Hats: I Like that. With my mother, my sister lived in San Diego and I live in Boston and my older sister lives in Boston too and we have some challenges like long distance caregiving. We had some challenges and just our personalities are so different. I think the difficult conversation that went really well was realizing that my younger sister was the companion. Okay, it was she the one who physically she lived yeah near her, so she would go spend time with her. They would go out together. She was present. She would hang out with her. Right but forget business and forget health. My older sister had no interest in the health aspect. So that was me. Okay, so she was the business person. Yeah. You know the finances and after she passed it was being the executor, and so we each once we figured out, we couldn't expect more of each other than we could do and I find as a boss I found that you know in my years as a boss. I'm happy to say I'm no longer an employee or a boss, but I think one of the hardest things was right-sizing the roll. Yep, so that you know, I got myself in trouble because I would just wish an employee who was a good-hearted good worker wasn't doing something, I thought they should do right. It wasn't really right for them.

Patrick Egan: Right or wasn't the way you would do it, right? Yeah, which and so I feel like they helped each other. That you know that dilemma. Well, I think what you're describing too, it's kind of like a job description and for me, you know the really vague. And by the way, vague job descriptions are the worst kind because you never really told are they doing their job or not. And so with caregivers, you're going to take care of Mom. Well, what does that mean when you unpack it? Like you say there is a health aspect in my own family. I have one sister that's registered nurse. She lives in Minnesota. I have another sister that is extremely good at organizing and cataloging and inventorying information. She lives in Alaska. I'm in Colorado. So, we really were atomized, and we were split all over. So, we had to do a lot of kind of remote planning without calling it that is just yeah, we would call and talk who's going to do this and I

think eventually without being planful about it. Each of us had an area of specialty we fell into. So my one sister is particularly good at the medical aspect. She's like I say a nurse and so not all, but most questions related to that go to her. And so, we've done that same thing and I think if you can planfully do that, it's even better. I think a lot of times it just happens that quite honestly in our family is based on proximity. Who live closest mom? you know, it was going to be involved my stepdad when they fell, or something happened. But as now as we realize that, you know, this new phase of life could be 15 years could be a long period of time. How are we going to work together to help them?

22:23 Effect on partners and family in caregiving?

Health Hats: I have one more question. I think I read that you partnered. Okay, [so 30-some years.] Okay. Well congratulations. [Thank you] 43. So, it is an accomplishment. how has caregiving impacted, a partnership, relationship?

Patrick Egan: Well, my partner, his mother is also older and is living in Omaha, Nebraska and she has three sons, two of them live within a block or two of where she does and then my partner Phil who lives in Colorado and so I think on one hand it strengthened our relationship because we each doing it in a different way being caregiver. He's probably more the practical financial person for his parent as well. And so, I think it's strengthened in that way. And then sometimes I think to your point of being able to have somebody that you can, for like a better word, bitch to or when things aren't going well, or you're just fed up it's nice to have somebody who's kind of going through the same thing. We're roughly comparable age, so actually, our parents are roughly comparable in age as well. So, some of the same issues that one of them will have will eventually affect the other one. and I would say probably the other thing that's just a challenge as we get older is jus, for lack of better word, feeling tethered like you feel Tethered to them. And so we're not as carefree as now as we were, you know, 10 -15 years ago, and we could just pick up and move or go on a month-long trip and not think about oh, you know, there's a couple of one or two people that are like relying on you and you can't just leave without having a plan et cetera. That's been a bit of a damper, but I think it's also it has its own rewards, but it's just something that has happened as we've gotten older. I don't know if that's a good answer, but that's us.

Health Hats: It's just interesting to me. Yeah, you know, I mean, I we have been care partner for my grandmother, my mother and a son on their end of life journeys.

Patrick Egan: Oh, I'm sorry. That's a lot. I have not done all that. Especially with the son, I can't imagine.

Health Hats: As you said, there it is. I feel like it - there was a strain. But I also am very proud of the family. we did it together, and even with my grandmother my kids were really young, and they took the brunt. It was really difficult, and they took a brunt. But with my mother and their

brother, they were older and they just they were there. We're tight because we been through stuff.

Patrick Egan: Well, if not only that but my mom had about a year ago, she had a fall, really serious fall. She had worked yet back surgeries was a hospital then had to go to a rehab center and it was a really eye-opening for me because it was a temporary rehab center. You go there between staying at the hospital and ultimately going back home which where she's now.

25:20 Having no family or support

Patrick Egan: But some people don't have that. Yeah, and they have family members that just either can't or won't or don't perform that and they don't have a circle of friends that can do. It's really sobering to realize that there are people that are just alone, and you know, it is a gift to be able to do it and to have that done with you. And so, I think about that myself, you know, like what is the future and do I have like a support system whether it's related by blood or not. But who's going to be there for me? And how am I gonna plan for things? You know, I don't think about it in the near term. You know, it'll happen.

Health Hats: Well, we were living in Upstate New York and our sons both moved to Boston. Okay, and my sister lives in Boston. So, my wife and I quit our jobs, sold the house, moved to Boston and now my older son and his family live upstairs. We bought a duplex together. [Oh wow], and my other son lives 10 miles away. [So, it's really blended family.] And I got diagnosed with MS when we got to Boston and I think, oh my goodness.

Patrick Egan: Wow, you'd already made the move?

Health Hats: We'd already made the move away. And so even though I probably had it for 25 years.

Patrick Egan: Yeah, you didn't get the diagnosis.

Health Hats: I just knew something was wrong. But I feel like you cannot predict the future. I don't believe in expecting stuff from people. But on the other hand, there we are and they're very attentive.

Patrick Egan: What are you describing is you created a safe haven for someone else but now you're going to live in yes. Yeah, that's pretty cool. That's good. That's a good story.

Health Hats: All right. Thank you.

27:06 Jalyon Hallows: Discovering the first time health was fragile

Health Hats: I spoke with Jolyon Hallows. Jolyon cared for his wife who had Parkinson's Disease for more than 20 years. He wrote a book about his experience *A Parkinson's Life and a Caregivers Roadmap*. I'll include a link to Amazon in the show notes. I also asked Jolyon, if he remembered where he was when he first discovered that health was fragile.

Jolyon Hallows: I don't know. I know that I can answer. I can answer what I was doing when I heard my wife's diagnosis. She had Parkinson's. I remembered vividly we were walking along towards a park called Central Park in our home in Burnaby, British Columbia to a path called, Rhododendron Walk. We were walking along, and she'd been quiet for a few days, which was uncharacteristic for her, and she said I went to see a doctor yesterday. He told me I have Parkinson's. And the other thing is that I don't I didn't have any emotional reaction to it. Okay. She made you might as well as said she needed to get her hair done. It didn't seem to register. But I still remember exactly where I was. Yeah, so it did have a it did have an impact.

28:33 Dealing with negative emotions

Health Hats: You just were giving a talk about the negative emotions, Harnessing Negative Emotions. So, did that topic come about because that was like a struggle for you at one point.

Jolyon Hallows: That topic came about I've been through all the emotions negative emotions in caregiving anger and rage and frustration and despair. You name it, I've had it in spades. And I was at last year's conference here National Caregiving Conference and emotions are negative emotions are big part of it. A lot of the sessions dealt with handling negative emotions and I saw a lot of the Serenity Prayer in evidence. Three or four speakers put up the Serenity Prayer. I I didn't mean but to me, but then I was flying home and going mulling over the conference and it suddenly struck me. What horrible advice this was. Because if I was in the grip of anger and someone told me I had to be Serene I would not have responded well and if they said if they implied, I wasn't serene because I lacked wisdom now, we're talking indictment for assault. So, I and I begin to think about these negative emotions and thinking about you know, we're they're there for a reason and instead of fighting them. We should be using them and that was the that was the basis for the talk that I put together.

30:14 Impact of information technology and project management on caregiving

Health Hats: That's great. I was looking you up. In preparation for this, this conversation and I saw

Jolyon Hallows: my mug shot

Health Hats: I saw that you have expertise in information technology and project management, and I was wondering how has that benefited you as a caregiver?

Jolyon Hallows: Well. I'm an ex-computer geek. I was a computer programmer and systems analyst and then I moved into project management among other projects. And the thing about project management is that it teaches you how to organize work that has to be done. It's not just a random mass of activities. They had to be structured and put together and planned out. So that's the mindset that I bring with me everywhere and. It okay. I read everything is a project. Okay now right, initially I didn't realize I was a caregiver. It was a series of events that caused me to think uh oh, now we have a problem. I better think of a way to handle it. I was I was away on a client site for a couple of days. And I was on my way back home and I called my wife to let her

know. She didn't answer the phone. So, when I got home, she was there, and I said, how come you didn't answer the phone? She said, "I couldn't remember how to use it." Okay, that ends my going out of town days because I mean if she can't answer the phone and she can't work the stove. I think that because of certain background in technology, I've been able to adapt what technology tools are available more readily than someone to whom a computer is a black box. But I don't think that it's I don't think it's been a huge advantage. It's just the background that I bring.

Health Hats: It's not a huge advantage that you have expertise in IT?

32:39 If you could recommend one electronic tool what would it be?

I actually have experienced not that much technology that I find useful. [I know what you mean] When I say that I'm talking about technology related to caregiving so what's been? So, I guess I have two parts to that question. What's your experience been? And if you were to recommend one thing, one technology, one tool to somebody in caregiving? What would it be?

Jolyon Hallows: Google. Yeah. Look things up. Doing research is so much easier now than it used to be. I've done research in the past and you've got to go down to the library and sometimes a specialty library to find things out now <beep>. There it is.

Health Hats: Yeah. So, Google. That's great, It isn't like something really fancy. No. No, it's not. It's something Google is pretty fancy under the covers.

Jolyon Hallows: That are covered under the covers it is but in terms of its function, it's no different than the library. It's no different from The Great Library of Alexandria., It's a collection of information. It's a lot easier to get at because of the technology that underlies it but it's the same concept.

34:08 How did IT and project management inform caregiving?

Health Hats: I'm making an assumption, so correct me if I'm wrong. I'm making the assumption that you had a career in information technology and project management and it overlapped with your career as a caregiver. In the period where there was overlap how did caregiving sort of back into your career of Information technology and project management. Like how did the caregiving inform while you were doing both?

Jolyon Hallows: I wouldn't say one informed the other. I would say caregiving more intruded upon the other. As my wife declined and Parkinson's is a progressive disease. As she declined I had to back off from things that I was doing. I had to start saying no to clients. I had to essentially I had to slow down and eventually shut down my consulting business because I couldn't leave. So the impact it's as though the caregiving career if you like became like Pac-Man and gobbled up the other career. Did I prefer that? No, absolutely not. But that was the reality I was in. In my normal career I had choices, I could choose whether or not to take on an assignment. I could choose how to carry it out. No choice no choice in caregiving, correct? I

mean, of course I had a choice I could have walked away, but that wasn't going to happen. So, there were no choice in in the outcome and how to do it.

36:02 How was your family involved?

Health Hats: I don't know that much about you. And I don't know about your family and usually caregiving is a team sport. And I mean sort of beyond that the medical team, the family, the community, the neighbors. So, how did how did your community of family and neighbors, how are they involved in your caregiving?

Jolyon Hallows: We don't have any kids? Okay. Tried but it didn't happen. Have one brother who lives about 250 miles away and a sister who lives about 600 miles away. So, they're not they can't be involved day-to-day. But more than that, I purposely refrained from involving them. I didn't want to change the relationship. I wanted to do we brothers and sisters and friends. I did not want them to be surrogate caregivers for me and I absolutely didn't want to have the situation where my brother was going to call me and said, "you know, I'm just not in any mood to listen to the problems. I'm not going to call right now." I didn't want that. So I know a lot of people here this conference of talked about the value of bringing family and friends in and using them as a support network. I never did. For support I relied upon the professional people that were out there - the counselors and the medical staff and the caree staff and a support group that I joined.

37:36 Caregiver support group

Health Hats: Okay. Tell me more about that.

Jolyon Hallows: I was in a Parkinson's caregiver support group, Not for Parkinson's but for caregivers. And I resisted because to me support groups was touchy, huggy, feely, lots of handkerchief sessions and I just wasn't into that. That's never been part of my background. but I realized when I need to talk to somebody, so I went to this my support group meeting. I got to say, my first couple of sessions was name, rank, and serial number. That was it. But when I was out of quite surprised because there as no. Well, okay, so occasionally some people would get weepy but most of them is there were no tears. There was just a conversation with a lot of laughter. There was a lot of information. And a lot of people willing to listen. Sometimes I'd be having a conversation with someone. In a typical conversation the other person wants to chime in. It's a two-way street. Here it's a one-way street. I am I'm telling what's up with me. What's going on? What's going on in my life? What's happening? And then there's a conversation around that but they are attentive, and they were listening, and I found that to be really valuable.

39:09 How did you get respite?

Health Hats: Your wife had a long spell of Parkinson's.

Jolyon Hallows: She had it just over 20 years.

Health Hats: That's a long spell in my book. And so how did you get respite? how did you get away and clear your brain? And how did you do that over the 20 years?

Jolyon Hallows: There were three services I could take advantage of one is CareAid. There's a CareAid Home Care Department of the Health Authority and I could book CareAids for two or three hours so I could go out to a course or to a meeting then this day program. I found a day program for my wife so I drop her off at around 10:00 in the morning and pick her up a three and I had the day to myself I could go play a round of golf for you know, whatever I wanted to do and I made it a point for at least two days a week. One of those days I made it a point not to go home. I would get on the transit system and visit some part of the city I had never visited before and or you know, go window-shopping Ikea, you know that type of thing. Yes. Yes, and just to get away from it. And the third one was respite care. I put my wife in the respite for sometimes the longest was 10 days and I started doing that when I got a request from the project management courses from out of town. And so, she'd go into respite for a week while I went to this do this course. But then I started doing it for just because I needed a break. So, I go and visit my brother and I got to say that was hard the first time I did that because. You know, I can't count the number of times that I wanted to turn the car around and go back and beg for her forgiveness for putting her into this place, but I needed the rest. I needed the break. We all need a vacation from whatever we're doing.

41:27 Lay people talking with experts and entrepreneurs

Health Hats: Lay people, whether they're patients or caregivers, often encounter a challenge when talking to experts. Experts such as clinicians and researchers. I asked Jolyon to tell us about such an experience he had.

Jolyon Hallows: Yeah, there's these panels put on by a Parkinson's Center up in Vancouver and the Center

Health Hats: Like a Medical Center that has Integrated Services?

Jolyon Hallows: It is actually a University: Parkinson's research. It's one of the Centers of Excellence of the Parkinson's Foundation. And these people are knowledgeable up the wazoo. I mean, these people, they're brilliant. They're PhDs and they're researchers. I've been there and I heard them talking about Parkinson's results. When neurons in the region of the brain goes Substantia Nigra die. Wait a minute. If these Parkinson's neurons die, how does giving meds help? They don't die. They stop producing the neurotransmitter that transmits the signals from one neuron to the next. They're still alive. They still functioning perfectly. They're not able to produce the transmitter that carries the signal.

And that's an important distinction to make because if these if these neurons die, then giving the neurotransmitter would be like tube feeding a corpse. Wouldn't accomplish anything right. I see this type of thing all the time and I have to question, wait a minute, if you're getting that wrong? My standard question is if I'm talking to an expert on the expert says something that I know is wrong. I have to question everything else you said even if I don't know where it is?

Health Hats: Yeah. Wow. That's a great example. Because I also sit on different panels. In IT we think a lot about workflow and how the processes, tools integrate with the flow of the work. I carry that to life and I think that tools have to fit in the flow of life. People are talking about either technology or medical solutions and I'm thinking, "what life is this? What life flow is this going to fit in?" Yeah, like they don't really understand life flow and so it's like the tool isn't going to work. I appreciate what you're saying.

Jolyon Hallows: What you just said is a problem not just in health but in technology generally I've known all sorts of people who here's the technology. Let's use it to solve them. Let's use it to solve the problem. What's the problem? Well we don't know but we'll use it anyway, I t's technology as a tool as you say to do something to improve something versus technology just because it's there and it's going to take over.

Health Hats: In health technology and apps, I find people talk a lot about how are we going to engage people to use this? And I find myself saying what you've got it ass backwards. Yeah first there's a problem that needs to be solved and this is a solution, the solution, one of many solutions, a partial solution. But if you've developed something and now, you're trying to think about how are you going to get people to use it? You've missed the boat.

Jolyon Hallows: You missed the boat. And I see this all the time that if you really want to get people to use what you've what you've developed to solve the problem. First, you have to convince them they've got a problem. Because they're not even they're always aware of it. I mean they're going through life and okay, they've had to make some adaptations and think might be better if, but they don't see it as a real problem. One of my jobs as the technology consultant was convincing people. Look you got a problem here because of whatever is going on. This is costing you this amount of money. I've stood up before management committees and said by not doing. by doing things this way it is cost you these many million dollars a year and they go oh, okay. So, what do we do about? Do I have a solution for you? But until they ask that question I could go in there and talk to almost blue in the face.

47:10 Solving caregivers' problems

Health Hats: Take this now to caregivers. Yes. my experience with caregiving and with caregivers is that the primary posture is head down? They're just busy taking care of business. Yes, and it's really hard to step back and be thoughtful about the process of caregiving to break it down to see that there's a problem and then look for a solution because their heads down and they're busy. So, have you seen, in your experience, problems that people don't really know they have that there are solutions to?

Jolyon Hallows: In the support group that I'm in we get people coming who. It's not so much as they think they've got a problem as they don't like the way things are. And when we talk to them will say have you thought of this? No, and it's almost a revelation to them that oh my goodness there's something else I can do. I came here just to you know to vent but I'm getting some real information that I can use to change. The trouble is that they have to want it. That's

why they're in support group because they're looking for something. Most people don't like change. This is the way we've is the which this is my rut because it's comfortable and getting out of a rut takes work. I mean even a literal rut it takes work to get out of that rut and a lot of people aren't willing to put in the work because they don't see the reward at the end. That's the challenge that I see in terms of teaching people how to do caregiving because they think they're doing it. And changing what they're doing is going to be something that it's going to take effort and I'm already swamped.

49:32 Conference calls, the family dinner table

Health Hats: You know when my son was sick, I think one of the best things that we did. So, this was fifteen years ago. His girlfriend's parents lived in Buffalo. We lived in Cobleskill, which was four hours or 3-4 hours away and Mike and his girlfriend lived some of the time with us or near us and some of the time near Buffalo in or near Buffalo. And we initiated a Friday [00:50:00] seven o'clock phone call that that her parents, the two of them my wife and I and my sons who were in different places. My other sons were in different places, but seven o'clock Friday night, we would all talk on the phone.

Jolyon Hallows: Like a conference call?

Health Hats: We would do stories of the week. Yeah, you know what happened a funny story, an appointment, a problem. Whatever. Yeah, and then

Jolyon Hallows: It's the family dinner table

Health Hats: Yeah virtual dinner table. Yes, is like before really, you know, I don't think we used, I can't remember whether the internet was there, but I'm not thinking of it anyway. Then we would look at what's coming, what's the week, you know appointments, what problems do we need help with? Yeah, you know who's going to go? Who's going to be where? Is somebody needed for an appointment who's going to do it? You know that kind of thing, it was like an hour a week. [Sounds wonderful.] Oh, it was wonderful. And it was again, it was like Google. It was you know an electronic tool that I don't know how we would handle stuff and the love. Yes, you know of just yeah dealing with this. Yeah, you know people looking awful this together.

Jolyon Hallows: Yeah people looking forward to and wanting to come together and support.

Health Hats: Sometimes it was like hard stuff like I would I would have been on the phone with his girlfriend's mother. And having a conversation about something that his girlfriend hadn't had a chance to share with her yet. And I was out of bounds. I can remember the call where I got called on that, like did that was inappropriate which was inappropriate.

Jolyon Hallows: It was accidental, and it wasn't mean-spirited.

Health Hats: It wasn't all love and wonderfulness. I mean it mostly but as much as can be in that situation, but it was also boundary setting and roles and responsibilities, and it was there was a technology aid.

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Jolyon Hallows: Yes. Yeah, you're right and sometimes those technology aids are just so simple.

Health Hats: You know Google. Not simple behind the scenes and the phone call wasn't simple

Jolyon Hallows: Conference calling is not simple behind the scenes. Yeah, and in fact, it hasn't been around that long outside, you know, very expensive professional or organizational use.

Health Hats: Thank you.

53:17 Closing: 4 of the 6.4 million family caregivers who are men

We've just heard from 4 of the 6.4 million family caregivers who are men. Although our caregiving experiences vary considerably you can't generalize about men in caregiving from us. What you can hear is that we found ourselves in caregiving before we knew what caregiving was. We did it because we could, and we wanted to. We had many emotions and stresses, and we needed and got help. We were not alone., We are proud that we have been caregivers. We all four are trying to give back to the caregiving community. You will find some resources in the show notes: links to my resource center and other resources. Starting with this episode I will include a link to a full transcript that can be read by the deaf or those who'd rather read than listen. Stay tuned for part 2 of this two-part series on Men Caregivers.

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