

Parents Are Hard To Raise S03 Episode Transcript

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[00:00:37] It's been said. Asking questions is the first step in meaningful change. No statement could be truer in the context of today's complex healthcare system. Diane's special guest expert this week registered nurse, Catherine Walsh, is here to show how her and her colleagues at the Change Foundation are opening the doors to better healthcare by asking the right questions.

[00:01:01] Join 180 million monthly subscribers who can now listen to Parents Are Hard To Raise on Spotify.

Diane Berardi [00:01:18] Welcome to Parents Are Hard To Raise. Helping families grow older together without losing their minds. I'm elder care expert Diane Berardi.

[00:01:27] As a caregiver... When was the last time someone asked you how you were doing? When a loved one is sick caregivers, especially those new to the role, face challenges and obstacles they may never have faced before. Today's complex health care system is getting better at focusing more on the patient and their concerns. But what about those family members involved in the patient's care? Don't they have needs, too? As a professional I've always felt the need to empathize with caregivers and their frustrations, but only now as a caregiver myself can I truly understand just how alone and helpless one can feel.

[00:02:10] My guest this week also knows what it's like to be both a health care professional and a family caregiver who not only understands the caregivers plight but is working on ways to make you better. Catherine Walsh she's a former researcher turned critical care registered nurse and now co design lead and educator for the connecting the dots for caregivers project at the Change Foundation in Ontario, Canada. Catherine Walsh, welcome to Parents Are Hard To Raise.

Catherine Walsh, RN [00:02:38] Thanks Diane. I'm so happy to be here and share this with you.

Diane Berardi [00:02:41] Well we're so happy to have you. Well I'm thinking, why don't we start with your personal story first. How did you come to be doing what you're doing now?

Catherine Walsh, RN [00:02:52] It's actually really interesting because I was working as a critical care nurse and I had an opportunity to become a nurse educator and one day I was asked to attend a conference in Toronto with the Change Foundation where I got to learn all about caregiving and also learn from the other teams and find out what co- design was which I had never heard of. And actually so I became involved with the project at that time but it wasn't actually until a couple months into the project that I started to realize that I was a caregiver as well. So it really starts to magnify that idea that even working in health care and being a caregiver in my own personal life it's not something I identified with. I was a mom or a granddaughter taking care of those people that I'm taking care of, but I didn't think of it as a separate thing. So this just going to the Change Foundation hearing about it and thinking I could actually be involved with a project that makes broad sweeping

changes for the lives of people in our community. It's such a rare opportunity and I was really really excited to be a part of it.

Diane Berardi [00:03:47] Now tell us about connecting the dots, that project.

Catherine Walsh, RN [00:03:52] Mm hmm. So connecting the dots is one of the projects that was funded by the change Foundation and the purpose of the project is really to look at our local community which is here on Perth. It's quite a vast rural area. Our biggest city is Stratford and we have 28000 people. So that gives you an idea of the grand size of the rotation.. There's a lot of farming communities that are very widely spread and so the information it's difficult for it to travel between. So connecting the dots, we came together as six health care organizations and we work together to really understand in our community what are the major challenges of caregivers and how can we improve that. And we did that through bringing 10 health care providers and 10 caregivers from a vast variety of experiences together for these biweekly meetings where we just really dug and tore apart, What does it mean for awareness and recognition of caregivers and how can we improve that in our local community? As our first step which was just one of three steps that we were working on.

Diane Berardi [00:04:52] It's amazing because people don't even know their caregivers.

Catherine Walsh, RN [00:04:55] No absolutely not. You think as a caregiver we heard time and time again, we have a video that I know it's been talked about before with Pat and she talks about the fact that she was just a wife and when we say just we don't mean I'm just a wife but you really think of that as part of your role. I had to provide care for my child. But then what you don't think about is, we had a really great story and this is when everybody in co-design team one, all of our perspectives just went "click." Because we had a mom say she had a child with multiple diagnoses and she went into her family doctor and said, You know I'm feeling really tired and I'm kind of feeling stressed and I don't know where to turn. And they said, Welcome to parenthood or something along that line. And although it's true that parenthood is exhausting my life as a parent with a healthy child going to school and not having any extra challenges is much different than a parent who's dealing as a caregiver as well. So I think we need to acknowledge that as yes it is part of the role is that as that friend, family, person in their life that you are going to provide caregiving. But that caregiving part is a separate entity that we need to nurture and support in a different way. And that's not something everybody has to deal with, although a lot of people do become caregivers at some point in their life.

Diane Berardi [00:06:10] Yeah. I was thinking well, when my mom got sick I wasn't identifying myself as a caregiver. Because I was I was going up. My husband is going one day a week to you know take her chemo and I was going up one day a week to do shopping and help her with everything she needs. You know help her. And I wasn't thinking of myself as one but all of a sudden you know I kind of got slammed against a wall and I was so tired and you know, I'm working and getting calls and trying to arrange all appointments, and having to take off if she needs to get to an appointment, and coordinating everything, and pharmacies and doctors etc. And then I'm saying... You know it hit me. And I'm in healthcare for 36 years, I'm like... I'm a caregiver.

Catherine Walsh, RN [00:07:02] Exactly.

[00:07:03] And that's the whole issue is the fact that we really want to stop caregivers from getting to that point. We don't want them to get to the point of burnout or exhaustion. We

want to... This time to talk toolkit was really a preventive measure so that physicians, nurses or volunteers... This is one of the great things about the toolkit as we've heard from volunteers, in our community we have a service that takes picks up people and takes them to their appointments and in the past the caregivers will speak to them and they didn't have anything to give them. But now even in that situation they can hand something over that provides some support to that person and gives them some information about the things that you're speaking about so that we can start to avoid that before it happens because nobody should get to that point. And that is really what has been happening and that makes an extra burden on our health care system.

Diane Berardi [00:07:51] Now tell us about the "time to talk" program.

Catherine Walsh, RN [00:07:54] Sure. The time to talk Tool Kit was created from our co-design team one. And really, as I said before, we had these three streams, one was awareness and recognition. And we realized really quickly that we needed to do these streams sequentially because we couldn't address communication or education if people weren't recognizing that role. Right. So yeah. So we got together and we talked about how can we do this how can we identify caregivers. And we went through a number of different things their co-design including the idea of sitting down at the... We were we were piloting it in our primary care, sorry, a family doctor's office. And we wanted to see thought maybe we can call every single person in the doc.. A patient there and say, Is there a caregiver involved with your care? But you know that seems ridiculous and it was ridiculous. There's no way we could possibly do that. We had to come up with a way that had more of a broad sweeping impact for both health care providers and caregivers to recognize the role and also have a resource. So we created this collection of resources that was created for both health care providers and caregivers to understand the role and associated challenges. And then the co-design processing created that. So the great thing about that is we had both health care providers and caregivers from community, hospital and family doctor experiences and beyond. So now this toolkit can be used anywhere because it has had all that input from other people. And it wasn't it's not about one person creating and thinking this is what we think would be helpful, it's about the users creating it out of what would be helpful to them or what was helpful to them.

Diane Berardi [00:09:28] Because not only I guess identifying yourself as a caregiver but, we all have, you know caregivers, have the same needs. We all have different ones too.

Catherine Walsh, RN [00:09:40] Exactly it's... Yeah 100 percent. And so the thing with the toolkit is that it really addresses that awareness and recognition but from two different perspectives. So it has a double edged meaning with the time to talk. It's not just trying to talk to providers but it's also time for caregivers to talk to each other and come to providers but also so for caregivers it helps them do that self recognition and mitigate that burnout. So they're not going to have burnout and prevent it. But for health care providers they knew there were caregivers that they were caring for or patients with caregivers but they didn't know how to engage with them and they didn't know what resources to provide. But also there weren't any resources to provide. So you know we had this kind of joke. OK. Congratulations you're a caregiver. Now off you go.

Diane Berardi [00:10:24] Right. [laughing]

Catherine Walsh, RN [00:10:25] I was not going to give them. So who wants to say that? Instead you just pretend it's not happening. You don't want to talk about it. So it was this toolkit that we created so they could say you know I think you know I recognize you as a

caregiver. This definition of a caregiver. Here's a pamphlet I want you to take this home and take some time to read it and read through all the different pieces of that which are you a caregiver? The impacts of caregiving. And those impacts are everything from financial to mental health, the relationship changes the fact that you know you go from if it's a spouse a romantic relationship to a relationship where you're that caregiver. It changes everything, in that the grief that you're going through that process. The signs of caregiver burnout and then how to deal with those that the encouragement to talk to someone a friend or family member. And we saw, time and time again, that people once they spoke you didn't we didn't have to have any grand solutions although grand solutions need to come in that's the next parts of our project. But if they spoke to someone and someone listened to them, then their whole body posture changed. They would walk into the room feeling stressed and you could just tell the burden that they were carrying and they lightened up as soon as they started to tell their stories and other people shook their heads nodding. I was brought to tears on so many occasions just watching this room of caregivers all nodding their heads you know furiously, because they're like, Yes! Somebody finally gets it. We went through so many boxes of Kleenex just because they were finally listened to. And for years they just felt in the dark and isolated.

Diane Berardi [00:11:59] It's you know that isolation. And I think.. You know when I think about isolation like I think of myself I'm saying, I don't want to talk to anybody. I don't want to go out. I don't want to... I don't want to do anything and then I don't know. I don't know if it's you don't want to be around people because, well you're tired. You don't want to talk to them and you don't feel you know... You don't want to be a drag and make people feel bad and get them down, but then also I'm thinking I don't want anybody to ask me for anything else. [laughing].

Catherine Walsh, RN [00:12:33] Right. Yes. Totally. And then we heard that and we also heard they don't want to be asked anymore how the person is.

Diane Berardi [00:12:41] Yes.

Catherine Walsh, RN [00:12:42] And it's that whole you know you want to you obviously want to be supportive for the person you're caring for but sometimes you're just tired of talking about it.

Diane Berardi [00:12:49] Yes.

Catherine Walsh, RN [00:12:50] And you're tired of it being all about them. And Pat does a really great thing in the video where she kind of moves sideways and waves and says hello I'm over here because people don't see you. So it's I totally. Yeah you get it you kind of isolate yourself so that you can protect yourself.

Diane Berardi [00:13:05] Yeah. And then and that's no good.

Catherine Walsh, RN [00:13:09] No. Not good at all.

Diane Berardi [00:13:11] And I would tell people constantly, No you can't. You know you have to do these things. But then you could I could internalize and realize oh my gosh I'm doing that. You know?

Catherine Walsh, RN [00:13:23] Well and I think that's what came to me as I realized when my grandmother was that she had heart failure and I wasn't a nurse at that point. So

I knew very little about heart failure. I was told, watch her salt and we should weigh her every day but I didn't really understand anything more than that. So being the person who brought her all her food and visited her every day and I had a newborn child, it was a lot of work. And it wasn't until like I said six months into this project that a light bulb went off and I thought oh my gosh I was a caregiver for her. And it's just not even addressed it's not something you think about. And you just you make it work.

Diane Berardi [00:13:59] Yes.

Catherine Walsh, RN [00:14:00] And you make it work and the other big thing is that caregivers want to do this. This isn't always, maybe not always, but a lot of the time this is something that they find very fulfilling and rewarding. We just need to find better ways to support them so it doesn't have a negative impact on their own life.

Diane Berardi [00:14:16] Right. Yeah. And that's the challenge. But that's the key.

Catherine Walsh, RN [00:14:24] Yeah. For sure. Yeah. So the caregiver tool kit the time to talk toolkit. There's the pamphlet as I talked about. But how do we get people to pick up that pamphlet? That's the question. So we put a poster on the wall anywhere we can. It's double sided and we actually have a adult double sided version and a child double sided version. Because so often people think caregivers are just caring for seniors.

Diane Berardi [00:14:47] Right.

Catherine Walsh, RN [00:14:47] That's...they don't think about the rest. So we put a call out on the some poster that says I'm honored to care for my dad or my mom or whatever the poster is but I'm tired and overwhelmed. I don't know where to find the information I need. Because we found that caregivers didn't want to pick up information because then they felt guilty for admitting they were overwhelmed and tired.

Diane Berardi [00:15:09] Yeah definitely. You're thinking, Why am I tired? You know I have to be strong, I have to just keep going. You know you think about tasks.

[00:15:20] We're going to continue talking with Catherine Walsh of the connecting the dots for caregivers project at the Change Foundation. But first, if you're a woman or there's a woman in your life there's something you absolutely need to know.

[00:15:35] I want to tell you about my friend Katie. Katie is a nurse and she was attacked on her way home from work. She was totally taken by surprise. And although Katie is only 5 feet tall and 106 pounds she was easily able to drop her 6 foot 4, 250-pound attacker to his knees and get away unharmed.

Katie wasn't just lucky that day. She was prepared.

In her pocketbook, a harmless looking lipstick, which really contained a powerful man stopping aerosol propellant.

It's not like it was in our grandmother's day. Today just going to and from work or to the mall can have tragic consequences. The FBI says a violent crime is committed every 15 seconds in the United States. And a forcible rape happens every five minutes. And chances are when something happens, no one will be around to help.

It looks just like a lipstick. So no one will suspect a thing. Which is important since experts say, getting the jump on your attacker is all about the element of surprise.

Inside this innocent looking lipstick is the same powerful stuff used by police and the military to disarm even the most powerful, armed aggressor. In fact, National Park rangers used the very same formula that's inside this little lipstick to stop two-thousand pound vicious grizzly bears dead in their tracks. It's like carrying a personal bodyguard with you in your purse or your pocket.

Darkness brings danger. Murderers and rapists use darkness to their advantage. We all know what it's like to be walking at night and hear footsteps coming at us from behind. Who's there? If it's somebody bad, will you be protected? Your life may depend on it.

My friend Katie's close call needs to be a wake up call for all of us. Myself included. Pick up a Lipstick Bodyguard and keep it with you always.

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Alexa [00:18:04] Getting the latest episode of Parents Are Hard To Raise. Here it is from my heart radio.

Announcer [00:18:09] It's as simple as that.

Diane Berardi [00:18:11] You're right Dolly! There are so many really cool new ways to listen to our show. It's hard to keep track. You can join the 180 million listeners on Spotify. You can listen in your car, at the gym or pretty much anywhere on your smartphone with Apple podcasts and Google podcasts. You can get us on Apple TV, Direct TV, Roku. And like Dolly said, you can even ask Alexa to play the show for you. It's great because you don't have to be tied to a radio anymore. You can listen when you want, where you want. For as long as you want. And if you're listening to the show one of these new ways please do me a big favor. Share this new technology. Help someone else learn about the show and show them a new way to listen.

[00:18:54] So Catherine we were talking about what's in the tool kit.

Catherine Walsh, RN [00:18:58] Mm hmm. So yeah I was talking a little bit about the posters. Yes. The main purpose of that is really a call for caregivers to pick up the pamphlet. We do hope that providers hand them out but we recognize that that's not always... They're not always going to be in a place where they can be handed out by providers. And we just needed to have a way that caregivers would connect and say, You know what, I need to pick this up and read it. And so that's the purpose of the poster.

[00:19:22] Then we have the pamphlet which I've gone over with you. And it's some quite a nice pamphlet. The last page of it is really a resource. So what we found is that people didn't know what resources to connect with in the local health care system. And although the health care system there are a lot of resources we just don't have the best way of

connecting to each other it's very fragmented and there's great resources that pop up and people aren't aware of them. In this pamphlet we have a quick reference guide for local people but that is really expanded on our Web site that we've created which is called CaregiversHuronPerth.CA. And this is a really exciting Web site. Although it's geared towards Huron and Perth counties in Ontario, any caregiver from all over the world could access it because what it does is it goes through each of the different things that caregivers would need: respect, spiritual, mental health support or transportation. And in those we have tips from caregivers. So what are in our interconnection groups or in our sorry, co-design groups, we've had all of the caregivers come together and list off all the tips they have for navigating the system. So often we that people walked around in the darkness not knowing what to do until they hit that right person who helped them get righted. So this Web site is that's what we've created to be that person that's always there 24 hours a day. And it's not a warm touch but it is another support for people. So it has tips but it also has a story. And that's meant for people to accept the resources, because we hear time and time again that caregivers say well there's probably someone who needs it more than me.

Diane Berardi [00:20:55] Yes you do hear that all the time.

Catherine Walsh, RN [00:20:57] Yes. And you know I had a caregiver in one of our groups and they're the person they were caring for had dementia and she had not declined a lot of the resources if they had been offered thinking I'm sure someone else needs it more than I do. And then finally she went to a group and she listened to everybody and the thought, You know what? I need those more than somebody else. [laughing]

Diane Berardi [00:21:15] Yeah.

Catherine Walsh, RN [00:21:16] So, in the end ended up taking some of the resources and I think we need to find a way to encourage caregivers to accept help.

Diane Berardi [00:21:23] Yeah.

Catherine Walsh, RN [00:21:24] This isn't something that they feel that they can do and especially interestingly not to bring it down to gender but men have a more difficult time accepting help.

Diane Berardi [00:21:33] Yes.

Catherine Walsh, RN [00:21:34] I think they often feel that they can't ask for help or I'm not sure what the reason is. But we do have a lot more women come forward. They want to talk about this than we do men.

[00:21:45] So we created a tip card, seven tips for providers. And this kind of gets to the other side of it. So we have this pamphlet to hand out we have the poster. But what do you say? How do you support these caregivers when they're in front of you?

Diane Berardi [00:21:57] Right.

Catherine Walsh, RN [00:21:58] And so we have a tip card that expands on these points but we also have a lanyard card because most health care providers have to wear their I.D. on something. And the number one thing is ask caregivers how they're doing.

Diane Berardi [00:22:09] Yes.

Catherine Walsh, RN [00:22:10] We actually spent months as a... And the change foundation trying to figure out what would be the best assessment tool. How do we identify caregivers? How do we find out how they're doing? And we heard from caregivers it just comes down to saying, Ask us. Just ask us how we're doing.

Diane Berardi [00:22:23] Yes. [laughing]

Catherine Walsh, RN [00:22:24] But make sure it's in the terms, How are you managing? Because too often, How are you doing? Sounds like you know, Hey, how you doing. You don't wait for the answer.

Diane Berardi [00:22:32] Right. Yeah.

Catherine Walsh, RN [00:22:33] It's just a greeting. So, How are you doing? Include caregivers as part of the health care team. They have more knowledge about what's going on with that patient than often the health care team does and they're really valuable and can decrease you know errors and keep all of that aligned. Share what's happening, what to expect next. Encourage caregivers to accept help. Help connect caregivers to resources. Encourage caregivers to talk to someone about their feelings. This is huge. We had caregivers who had never told anybody how they were feeling and it was just building up on them. And then revisit that conversation. One time is not enough. Sometimes people need to be talked at every appointment for two years before they feel that they're ready to open up in the office.

Diane Berardi [00:23:12] Right yeah. Open up, yeah.

Catherine Walsh, RN [00:23:13] You never know when that's going to happen. But all of these pieces are available on that Web site, so anybody, all over the world can go on to our caregivershuronperth.ca website.

Diane Berardi [00:23:26] Perfect.

Catherine Walsh, RN [00:23:27] Yeah they can click on either, I'm a caregiver or I'm a health care provider, you can access both. And if you look for time to talk in there all of the resources are there. They're downloadable there are print quality if a health care organization wants to use them or if someone wants to use them personally.

Diane Berardi [00:23:42] You know, when you were saying that what to expect next. I think that's a big one, too. Because I kind of... I'm just waiting. And I'm saying, You know what happens next? You know. And I find... Being in health care for 36 years, I have difficulty struggling through the maze in the health care system. It just... Nothing connects with the next step. You know like for my mom for instance she has an oncologist and she has a gastroenterologist. And it's like, Well which one do I go to for this?

Catherine Walsh, RN [00:24:26] Yeah, yeah.

Diane Berardi [00:24:27] And I'm trying to get a hold of gastroenterologist, he's not getting back to me. So then the oncologist says, Well I can help you with that. You know and then I'm like Okay. And then we have a gastroenterologist appointment, he changes what the oncologist prescribed. So it's like, Well who do I listen to? What do I do?

[00:24:45] Yeah. And nobody necessarily talks to each other unless you're on the same system somehow. Totally. Like I said in my biography, I became a nurse after caregiving for my grandmother specifically because I couldn't navigate the system and I was frustrated and nobody in my family is in health care. We're in fact in historically in my family, my family was even opposed to health care with their religious beliefs in the past. So this is something we don't know about and you have to have an advocate in your family.

Diane Berardi [00:25:12] Yeah.

Catherine Walsh, RN [00:25:12] There's just... It's difficult to manage. Some of our caregivers had been nurses or physicians for 30 years and they couldn't navigate the system. So it's really, we wanted to look at what is currently out there in our local community and how can we make this more accessible? Because it's out there. It's just... It's like play golf in the dark. You know that the hole is out there. You know there's clubs around you somewhere. But you just need the lights put on you can find what you need to get that ball down that green.

Diane Berardi [00:25:42] Exactly. I mean it is. It does. It gets you so frustrated then you're just you know... Sometimes I'm, Well that's it! I'm just not calling again. And that doesn't do anyone any good. But it's just so frustrating.

Catherine Walsh, RN [00:25:58] Mm hmm. And I think as health care providers we try to do our best to to be empathetic and understanding. But you're so focused on your task at hand that sometimes you forget about all the other gears that are moving. And I had a caregiver... A number of caregivers say when the lights go down at night or when the blinds close it's what happens behind those doors when they feel helpless. They don't know how to get help. And unfortunately everything happens on a weekend, a holiday or at night.

Diane Berardi [00:26:24] Right. Exactly. Why is that? [laughing].

Catherine Walsh, RN [00:26:27] I don't know. [laughing]

Diane Berardi [00:26:28] It's true.

Catherine Walsh, RN [00:26:31] It goes perfectly until that happens and then bam the wheels fall off. So how can we help people in those times that they don't feel alone?

[00:26:37] And that's key.

Diane Berardi [00:26:39] Definitely. And can you please give us the Web site again?

Catherine Walsh, RN [00:26:43] For sure yeah. It's WWW.caregivershuronperth.ca And once you open it up it's really... It was actually co-designed. So I feel like it's... I'm biased because I helped create it. But it's beautifully made. It's very easy to navigate and there's a video on there that you can watch to learn how to navigate the Web site. It's got just a lot of great resources that are easy to find and it just supports caregivers and providers.

Diane Berardi [00:27:10] Thank you so much. Catherine.

Catherine Walsh, RN [00:27:11] You're so welcome. This has been a pleasure and I thank you very much for including me.

Diane Berardi [00:27:16] Oh thank you. And Parents Are Hard To Raise family, I love getting your e-mails and questions. Please keep sending them in. You can reach me at Diane at Parents Are Hard To Raise dot org or just click the green button on our home page.

[00:27:28] Parents Are Hard To Raise is a CounterThink Media production. The music used in this broadcast was managed by Cosmo Music New York, New York. Our New York producer is Joshua Green.

[00:27:38] Our broadcast engineer is Well Gambino and from our London studios, is the melodic voice of our announcer Miss Dolly D.

[00:27:46] Thank you so much for listening.

[00:27:46] Till next time make you forget everything you don't want to remember and remember everything you don't want to forget.

[00:27:52] See you again next week.