

Parents Are Hard To Raise S03 Episode 124 Transcript

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Announcer [00:00:37] Even in today's high tech world virtually all of the care our loved ones receive will come from a family member. Yet rarely are family caregivers included in the care planning process. In Canada there are changes underway to fix all that.

[00:00:53] This week on Parents Are Hard To Raise Diane's special guest expert Dr. Leslie Nickell is here to tell us how.

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Diane Berardi [00:01:20] Welcome to Parents Are Hard To Raise, Helping families grow older together without losing their minds. I'm elder care expert, Diane Berardi.

[00:01:29] When it comes to caring, recent studies show that the vast majority of care a patient will receive will come from a family caregiver. Yet despite a health care system that relies almost entirely on family and friends to provide the necessary care, providers tend to leave caregivers out of the loop.

[00:01:49] There are actually some great and lasting benefits to partnering with caregivers, which is why some very smart minds in Canada are working to remove the barriers between caregivers and the health care system. My special guest this week is one of them. Dr. Leslie Nickell is an associate professor in the Department of Family and Community Medicine at the University of Toronto and has been a full time family physician for over 20 years. She is currently the medical lead for caregiver support services at the Bridge Point site of Sinai Health System where she is working to bridge the gap between family caregivers and health care providers. In addition to her medical training Dr. Nickell is also trained as a social worker which I believe gives her a unique perspective on the dynamics and challenges of family and community care. Dr. Leslie Nickell, welcome to Parents Are Hard To Raise.

Leslie Nickell, MD [00:02:47] Thank you very much. It's a pleasure to be here.

Diane Berardi [00:02:50] Well it's a pleasure to have you. And we were talking before we started the show and we were saying what great work you're doing.

Leslie Nickell, MD [00:02:58] Thank you Diane. It's a work in progress for sure.

[00:03:02] We have a long way to go but I'm really delighted we've gotten started with it.

Diane Berardi [00:03:05] Well we are too and we have a large worldwide audience of health care professionals who are listening. So if you can tell us, Leslie, why is it so important for health providers to engage caregivers?

Leslie Nickell, MD [00:03:22] Well sure, and I think you alluded to some of it in your introduction when talking about the vast amount of health care and care that families and caregivers provide to their family members or to their friends.

[00:03:38] And I think I just want to make that point right out at the beginning. If I use the term "caregiver," I think you know we often think it's always family. And it often is family, but sometimes it's friends. One time I had a situation where it was the hairdresser. So it can be whoever is sort of the most significant person in someone's circle of care.

[00:03:59] And often caregivers don't call themselves caregivers. So it's hard to kind of adjust to that name but you remember I'm the daughter or the husband but... So I just want to clarify that upfront.

[00:04:12] But you know we know that there's probably you know about 26 to 72 billion dollars worth of care is provided by caregivers. And every year in our province alone in Ontario we have well over 3 million family caregivers. And they don't just provide the care. They're also responsible for the whole overall organization of the parts of the care. You know in overseeing all those parts. And so why I think it's really important for health providers to be involved and engaged with caregivers is not just simply that they provide all that care but they actually provide better care. And we know that when we're engaged with our caregivers there's actual evidence that there's fewer falls, there's fewer medical errors, they're as less often a readmission for the same issue again. And there's just better coordination of care all around and a better experience for everybody. And you know it's such a, we were talking about it before we started, it's a fragmented system. It's very disconnected the health care system and the one constant is the caregiver. And I'm sure you've probably experienced this yourself in your own work but you know the caregivers come, they've got as equally large chart, a file that they bring with them.

Diane Berardi [00:05:45] Right.

Leslie Nickell, MD [00:05:45] And thank goodness they do because sometimes that's the only way that we can have consistent information that travels from specialist to specialist in hospital to rehab and hospital to community.

[00:05:59] So there are many reasons and I think it is the last thing I'll say about this is we know that the more engaged we are with caregivers the more engaged they become, the more capable that they feel, the more confident they feel, and the more they're sustained to do what is a pretty demanding role.

Diane Berardi [00:06:25] Why don't health care providers include caregivers?

Leslie Nickell, MD [00:06:29] Well I think there's a lot of reasons for that. And I also I will say I think we're getting... We're a long way from good, but we are getting a little bit better. There are some out there who are really trying to change their approach. And the fact that we're actually having this conversation it is you know indicative of that fact.

[00:06:49] But I've been thinking about this question a lot and I kind of break it down into three sort of main buckets. One is, and I'll use the word systems, There are lot of systems issues that we could you know unpack and talk about.

[00:07:05] There are beliefs and attitudes that I think come with individual health care providers. And then I think there's another sort of category of just sort of fear of the

unknown. And their own experience, because health care providers as we know are feeling pretty stretched and we read a lot about burnout.

Diane Berardi [00:07:27] Right.

Leslie Nickell, MD [00:07:28] And I think that inadvertently contributes sometimes to their reluctance. I don't know if you want me to kind of go through to the buckets.

Diane Berardi [00:07:37] Yes definitely.

Leslie Nickell, MD [00:07:38] Okay sure. So with these systems if you think about it you know we know it's they're under a lot of pressure and especially about costs and accountability, being efficient.

Diane Berardi [00:07:50] Right.

Leslie Nickell, MD [00:07:51] And there's a fair number of what we call metrics or the things that health care is measured by. And they're usually set out by bureaucrats, and government, and not particularly people who are actually delivering the care. But they don't actually translate into quality of life or actual care for individuals. There are things that are measurable but don't actually address the actual experience of what it's like to be receiving care in our system. Things like length of stay, for example.

[00:08:30] And so I think that's one problem because if everybody is having their feet held to the fire for these accountabilities then they're losing sight of what I think is a really important pieces around relationship and communication and quality of experience. So I would say that's part of the systems issue.

[00:08:54] And the way that we design our systems, if you think about it, you know we arrange rounds at times that no normal person is ever going to do.

Diane Berardi [00:09:05] You're Right. [laughing]

[00:09:10] You know we're used to and we're comfortable as health care providers, as professionals, to make the decisions and tell people what to do. We're not used to including them in shared goals, shared decision making around treatment and discharge and what's going to happen in the future. It's very unsettling I think for a lot of professional... all of our professions physicians, nursing, all the other different disciplines. And we're not trained actually to think like that. So it really is asking people to go out of their comfort zone and then that's where the beliefs and attitudes I think come in, because they think it's going to take them more time.

Diane Berardi [00:09:56] Right.

Leslie Nickell, MD [00:09:56] They think it's going to give them more demands. And it's actually quite the opposite because you engage caregivers. You you will benefit so much from the information that they bring about their family member. That it actually is going to save time and reduce complications and potential errors.

[00:10:23] And I can talk a little bit later if you like about an example of a caregiver that told me a story that was just you know really illustrates that point. So I think that's the second bucket.

[00:10:36] And then the third one around fear and burnout. They're fearful if they open up that they're going to have to give more. You know and if they connect that something more is going to be required of them. And that's again I think a really short sighted view of this because in fact. Very quickly what they're going to see is that there's huge benefits from engaging caregivers and learning from them and with them. Maybe would it be helpful if I gave sort of the one example that I was thinking of?

Diane Berardi [00:11:11] Yes please. Please do.

Leslie Nickell, MD [00:11:14] I don't want to just ramble. [laughing].

Diane Berardi [00:11:17] No it's great. We want to hear it.

Leslie Nickell, MD [00:11:20] So this was a... It was a caregiver she's in her 80s. She was caring for her husband who was in his late 80s and she was providing the typical sort of 24/7 care. He had multiple issues including dementia and diabetes.

[00:11:40] And just to kind of set it up, like she was doing all of it. Not just his care but she was managing the household tasks, the meals, coordinated all of his medical care. She gave him all of his medications. She was the one that monitored if he was you know changing in any way so that she could seek help when he needed it. She was up at night with him. She was all in.

[00:12:04] So she needed a break and was booking a respite bed for him for a week.

Diane Berardi [00:12:10] Ah. OK.

Leslie Nickell, MD [00:12:12] And the physician filled out the form that everyone at the retirement home needed the respite home needed for his care. And then she had to wait for the bed to become free. And in that time he had some medication changes. Most importantly, they actually discontinued his insulin. He didn't need it anymore. And so when she was just about ready to leave him in the bed, the doctor there said you know reviewed the medications and had him on was going to be giving him his insulin. She said, No no no. You know that's been discontinued.

Diane Berardi [00:12:50] Right.

Leslie Nickell, MD [00:12:51] Well they wouldn't believe her.

Diane Berardi [00:12:52] Oh my gosh.

Leslie Nickell, MD [00:12:53] And you know she kind of said, I really don't have any reason to lie to you about this.

Diane Berardi [00:12:58] Right. Right. [laughing].

Leslie Nickell, MD [00:13:00] And they actually required her to then go back to the physician who filled out the original form and get a new form.

[00:13:07] So you know it doesn't sound like a lot but all these appointments are a lot of time and energy. And she was already pretty empty and exhausted.

[00:13:16] And you know she in her oversight of his situation and being aware that they needed to change that medication, say did save that retirement home from a very problematic potential error, of giving someone insulin when they don't need it.

[00:13:37] It would have been a huge risk to her husband and to them.

[00:13:42] And I think she was underestimated, you know from the get go which is a very common story.

Diane Berardi [00:13:52] Yeah I was going to say. I'm sure. Oh my gosh. That poor woman and that poor man. Thank God it worked out OK.

Leslie Nickell, MD [00:14:00] Yes.

Diane Berardi [00:14:01] We're going to continue talking with Dr. Leslie Nickell.

[00:14:04] But first, if you're a woman or there's a woman in your life there's something you absolutely need to know.

[00:14:10] 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.

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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 [00:16:36] Getting the latest episode of Parents Are Hard To Raise. Here it is from my heart radio.

Announcer [00:16:42] It's as simple as that.

Diane Berardi [00:16:43] 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. Please share this new technology. Help someone else learn about the show and show them a new way to listen.

[00:17:26] You made such a great point Dr. Nickell. We were talking about losing sight of the relationship. And I remember in teaching classes I would say, you have to remember it's a person. You know, it's a person there that you're treating or you're taking care of. And it's a person that has a family or people that care for them.

[00:17:51] So that's a big, I don't know. You know in physician training or even nursing training I would say to nurses did you learn... Did you have sociology classes?

[00:18:05] I think that might... You know, that's a big problem.

Leslie Nickell, MD [00:18:11] Absolutely. It is a big problem. And I find it so perplexing because in fact for me you know the relationship and the connection that you have with patients and family, that's the most meaningful and delightful part of what we do. So I find it very perplexing when we seem to have a lot of health care professionals that have lost that somehow. And I don't think they intentionally lose it. I you know I think it is really multifactorial. And. You know there are the system pressures that we talked about and then there's also you know this is probably opening up a Pandora's box.

[00:19:00] But the electronic medical record has not been very simple transition. And for your listeners you know that's instead of having the paper files that we used to have which had all kinds of problems with them for sure. But now it's all on computer. And I see my trainees you know sitting at the computer.

Diane Berardi [00:19:21] Yes.

Leslie Nickell, MD [00:19:21] And I'm watching them through the mirror sometimes supervising and they'll be busy asking their questions and typing away on the computer, which is you know they need to make their notes.

Diane Berardi [00:19:32] Right.

Leslie Nickell, MD [00:19:33] And meanwhile the patient is crying. And I've actually had to phone in sometimes and say, Look up!

Diane Berardi [00:19:38] Yes. They don't. Yes. Oh my gosh.

Leslie Nickell, MD [00:19:42] Yeah... Yeah. And I do. I do think you know I've I've talked to a lot of people about this and there's some sense or theory that you know when people are feeling pretty stretched and burnt out themselves you know. They feel fearful. That they just have their in compassion fatigue, I guess.

Diane Berardi [00:20:05] Yes.

Leslie Nickell, MD [00:20:05] Is a term we read about. And so to connect with someone will require that I care about them, and that I'll feel compassion for them. And so... and I am not even sure it's conscious.

Diane Berardi [00:20:18] Right. Yes.

Leslie Nickell, MD [00:20:19] That ,kind of that sense of, I can protect myself and I don't engage, then I won't have to feel.

Diane Berardi [00:20:27] Yeah.

Leslie Nickell, MD [00:20:27] Which is such a shame because I really think that they are cutting themselves off from the very thing that is refueling them.

Diane Berardi [00:20:35] Right. Yeah.

[00:20:36] What happened that made you see the value of engaging caregivers?

Leslie Nickell, MD [00:20:42] Oh wow. So. So all it's a little bit of a story. But as you mentioned I uh I was in practice for well over 20 years and in family medicine. And my practice had a lot of very complex elderly patients with lots of different diseases and medications, and so too did my other physician colleagues. And that was actually before the days of the electronic records. So we had you know, "Volume 5..."

[00:21:17] Right. [laughing]

Leslie Nickell, MD [00:21:18] These massive charts. And you're supposed to see your patients in 15 minutes. And some people even try and do the you know, and you'll only can bring it one issue at a time. Which is ridiculous in a scenario like that. So none of us were feeling like we were doing a good job. And we knew that the patients were leaving feeling like they weren't really properly attended to. And so we started exploring different models of care and we actually landed on one that was very into professional model and quite unique in some of its components. And one of them was that the caregiver, the family caregiver, was an integral part of our team and our assessment. And there would be seven different disciplines that at the same time, real time, were what we would call, "unpack" the patient and the situation with the caregiver and with all these different professionals. And over a couple of hours you had a really good understanding of what was going on and what we could put in place as a plan. And it had a lot of good benefits but the one that

really dropped for me, the penny dropped for me was around the incredible value of bringing the caregivers in right from the beginning like that. And for them to be an integral part of every step of the way, both in the assessment and in the care plan, and then in the execution of the care plan. Because of course, none of that ever happens without caregivers being onboard.

Diane Berardi [00:22:57] Exactly.

Leslie Nickell, MD [00:22:57] And they were very clear why the care plan was what it was because they co-created it with the patient and with us.

[00:23:03] And so that was so rewarding. And it stayed with me for many years. And now I'm in a situation where I have an opportunity to focus truly on that part. And that's you know in part to the Change Foundation, which is an organization in Ontario, our province, that has been focusing on needs of caregivers now for a number of years and has funded four projects in our province and our hospital and community agencies were involved in in one of those or are still involved. So through that I've been able to continue to work.

[00:23:47] Leslie, so tell me about the, Partners In Care, education modules that you helped develop.

Leslie Nickell, MD [00:23:53] Oh yes. So again these are through the Change Foundation. And these are modules that have been developed for health care providers and it's not specific to any particular discipline. They will be relevant to all of the disciplines. And each module sort of has a particular focus.

[00:24:13] So the first is to recognize the role of caregivers. Because as we mentioned earlier, caregivers don't always acknowledge themselves as caregivers, and Health Care Providers often don't see them as caregivers.

[00:24:29] So that's the first thing as to how to recognize who they are. And then how to communicate with them.

[00:24:36] And that was the second module. And then the third module helped develop practices to really for health care providers to learn ways to help empower caregivers and to support them.

[00:24:50] So these are beautiful modules. My role was was not a hugely extensive, but I did review the content and because I now spend all of my time pretty much clinically talking with caregivers I could use that lens and think of their stories and make sure that we were you know identifying all of the kind of common themes. Everybody's journey is a little bit different. No two caregivers are exactly the same or no solution is going to work for everybody. But there are common themes for sure that we all share.

[00:25:27] And then the other piece was to really validate the time and energy that professionals would put into learning these things and doing the modules they get what we call continuing education credits, which every professional discipline needs to have to sort of keep their license or registration current.

[00:25:51] And so this it gives them something back and it also acknowledges how valuable or important we think the content of these modules is.

Diane Berardi [00:25:59] Definitely.

[00:26:02] Leave us with one key takeaway you have for other health care providers that are listening around the world.

Leslie Nickell, MD [00:26:08] OK and I have thought about this. It's hard for me to think of it took to put down in one. But..

Diane Berardi [00:26:17] You can do two. [laughing]

Leslie Nickell, MD [00:26:19] I think, I think the... Well I'm going to start with this one. Which is I think, Try to be mindful of the assumptions that you make.

[00:26:29] We tend to do that and we're not even aware that we're doing it.

Diane Berardi [00:26:34] Yeah.

Leslie Nickell, MD [00:26:34] And so, because of those assumptions we then tend to either discount that someone's going to you know be helpful or they're going to be demanding or you know don't give this one eye contact because they're going to ask me something.

[00:26:52] Don't make assumptions that, you know even about the relationship, because these relationships are complex and you know I've been in a caregiver role too and you know you'd bring all of that history with you to that caregiving role.

Diane Berardi [00:27:04] Yeah.

Leslie Nickell, MD [00:27:05] And so, I think as health care professionals we need to be mindful that no particular day is the same as another day. And that caregivers may be feeling more or less loving or more or less capable on any given day. We need to be aware of that.

[00:27:29] And that they may appear to be doing fine. But it's important not to just take that at face value but to really listen and be aware of how they are doing.

[00:27:44] Ask how they're doing.

Diane Berardi [00:27:46] Dr. Leslie Nickell, thank you so much for being here.

[00:27:52] Oh thank you for having me. I really enjoyed talking with you, Dr. Berardi. Thank you for caring for caregivers.

Diane Berardi [00:27:59] Thank you for doing the same and all the work you're doing.

[00:28:07] Parents Are Hard To Raise family, I love getting your e-mails and questions so please keep sending them. You can reach me at Diane at Parents Are Hard To Raise dot org or just click the green button on our home page.

[00:28:17] 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 Joshua Green. Our broadcast engineer is Well Gambino. And from our London studios, is the melodic voice of our announcer, Miss Dolly D.

[00:28:33] We love our parents but parents sure are hard to raise. Thank you so much for listening.

[00:28:39] Till next time... May you forget everything you don't want to remember and remember everything you don't want to forget.

[00:28:45] See you again next week.