

## Parents Are Hard To Raise® S03 Episode 111.mp3

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**Announcer** [00:00:37] Today's healthcare system is offering up new hope for so many, but it's not without its own twists and turns bumps and bruises. Few know the snags and frustrations better than caregivers, but mostly, their voices go unheard. One amazing organization in Ontario, Canada is changing all that. This week on Parents Are Hard To Raise®, what the world can learn from Canada's premier healthcare think tank, the Change Foundation.

[00:01:07] Join 180 million monthly subscribers who can now listen to Parents Are Hard To Raise® on Spotify.

**Diane Berardi** [00:01:26] Welcome to Parents Are Hard To Raise®...Helping families grow old together without losing their minds. I'm elder care expert Diane Berardi.

[00:01:37] It often seems the more advanced our health care system becomes the farther it strays from the old fashioned, compassionate, personal care we all need, want and desire. All too often, in our rush for excellence, procedure trumps purpose, and caring and compassion are the casualties.

[00:01:58] By listening to patients, family caregivers and health providers the Change Foundation is driving a new breed of health system, one that is transforming the way care is delivered, and in turn, benefiting everyone it touches.

[00:02:13] In today's health care system there are some of us who use change to promote their careers. And then there are those, like my two guests this week, who use their careers to promote change.

[00:02:26] Christa Haanstra is a visionary. She works with the Change Foundation in Ontario, Canada. And Carole Ann Alloway, a caregiver herself, is making sure that the voice of the caregiver is never silenced. Christa and Carole Ann, welcome to Parents Are Hard To Raise®.

**Christa Haanstra** [00:02:44] Thanks.

**Carole Ann Alloway** [00:02:45] Thank you. Excited to be here.

**Diane Berardi** [00:02:47] So I guess I'll start with Christa.

[00:02:49] Tell us about the Change Foundation and your role there.

**Christa Haanstra** [00:02:54] Sure. So the Change Foundation has been around for about twenty five years and we try to be one step ahead of the health care system and see what's coming around the corners of the health care system and prepare our providers and patients and caregivers for that change. So most recently our focus has been on how to better recognize, identify and integrate family caregivers into the health care team and to support them at home.

**Diane Berardi** [00:03:24] So, you started working with caregivers about five years ago?

**Christa Haanstra** [00:03:29] That's right.

[00:03:30] We're about four years into our five year focus on caregivers.

**Diane Berardi** [00:03:35] And you were speaking to them and trying to understand their experience.

[00:03:40] So what did you learn from that?

**Christa Haanstra** [00:03:43] Yeah. So we actually went across the province and met with about 300 caregivers, and in different parts of Ontario urban, rural, remote settings. And obviously every experience is unique.

[00:03:57] And so we heard 300 different stories. But ultimately we heard kind of four common things that sort of been the driver behind our work in the last four years. So we heard that better communication is needed between providers health care people who work in the health care system and family caregivers. And between providers, so when people are transitioning maybe from their family doctor to a home setting or whether they're going from hospital to home there's a lot of times where the information falls through the gaps. And the family caregivers holding that information and that's very stressful. And you know this is sometimes in an emergency situation where you know this is all new and so it can be very stressful.

[00:04:43] And, wanting to have some kind of assessments and not just assuming that if I'm sitting beside my loved one in an appointment that I can just take them home and suddenly do dressings or check their blood sugar levels or whatever.

[00:04:56] And, the third was recognition. So the idea that people want to be recognized and identified for the role that they play and valued for that role.

[00:05:05] And then education. So again that idea that you can't just send me home and assume that I know how to fix... To take care of a wound or to change a central line. You need to show me how to do it and to make me feel confident that I can do it.

**Diane Berardi** [00:05:22] Yeah exactly.

**Christa Haanstra** [00:05:24] Yeah. That's been driving our work in the last four years.

**Diane Berardi** [00:05:27] It is unbelievable. And everything you say... I've been in health care for 36 years and I'm a new caregiver to my mom and now my dad. And it hits you, it comes upon you. And there is no preparation, there is no, no training. And you do feel that you're out there on your own. A lot of times.

[00:05:50] And I think the hardest part is, you're part of that patient. You're part of their lives, you're part of their story, they're good and bad every day. But no one recognizes you in the part of their team. You know, Doctors, nurses. Right?

**Christa Haanstra** [00:06:09] Yeah. And I think sometimes you know a patient wants to put on a good face when you're sitting in front of their provider and you know if you turn to the

caregiver and said, Well you know is that your experience over the last few weeks, is that what you've seen, or what have you noticed most about the changes or whatever? You would get a very different story, because they're often the ones who are dealing with the fallout of that. And so I think it's really important to think about that recognition. I think the way that you started the show and just talking about, you know in our rush for excellent...

**Diane Berardi** [00:06:40] Yeah.

**Christa Haanstra** [00:06:41] We often forget about the compassion and the humanity, and at the end of the day. This is all about humans. Right?

**Diane Berardi** [00:06:46] Right. You're right.

**Christa Haanstra** [00:06:48] And human relations. And that's what's most important.

**Diane Berardi** [00:06:51] And I think that's what happens. You know, it seems people become just another number. And they're another case and no one looks at that human, the patient, you know as a human being, and the caregiver.

[00:07:04] I can't tell you how many times a son or daughter comes in with their mom or dad, and they're caring for them. And the first thing I say when I'm teaching is, Look at that caregiver. You have to open your eyes not only to that patient but to that... You can just look and you can see their appearance or how they carry themselves or they're dragging, you know. And I've been in a room with doctors and nurses and no one says to them, How are you doing? You know so this is... So what you're doing is just, is so vital.

**Christa Haanstra** [00:07:42] And I think the thing that we kind of forget, because we're talking about humans who work in the health care system and those who are coming in, and I don't actually think it's fun for the people working in the health care system to not have the time, or the information, or the ability to help the caregiver. I think there's where they're busy. The system is set up in a way to value different kinds of interactions, and the focus is on the patient and the patient outcomes, and not necessarily about the caregiver. So I don't actually think it's health care providers and professionals who are just ignoring the caregiver, necessarily. I think it's that that's not what they are...

**Diane Berardi** [00:08:23] Supposed to do.

**Christa Haanstra** [00:08:24] Expected to do. Exactly. Exactly.

**Carole Ann Alloway** [00:08:28] I also think that part of the problem are the metrics that are used. So for instance, for a certain surgery you have to be out in three day. You could only be in a bed for three days. And when in fact that person may not be ready to go home until five days. But the measurement is three days. Or someone might be ready after a day, they recover really well. So I think metric sometimes drives what's happening. And we don't look at the whole person.

**Diane Berardi** [00:08:56] No you're right. You're absolutely right. Because that's what it says. This diagnosis, three days. And they don't think about the transition or that person going home. Do they live alone? Do they have a support group? Do they have someone to give them food?

**Christa Haanstra** [00:09:16] Or is that daughter who's sitting beside them in the in the appointment room living two hours away? She just had the be here today.

**Diane Berardi** [00:09:23] Exactly. That's my difficulty. I'm like two hours away. And even to a simple thing where scheduling. You know, I say, Could you put it in my mom's system? Because they just hand my mom a piece of paper, for her chemo. And they give her the times. And I say, Mom, just take a look. Just say to them, is it 11:00? Because that's the best time for me or my husband to get her there. And every time she'll say, No. My appointments 1:30. And so I call and I say, okay my mom forgets or she can't read it and... I call and I say, Could you just put it in her chart. Can you put an 11:00 appointment, because I come from two hours etc..

[00:10:02] "Oh... Well there's nowhere to put it. Like...

**Christa Haanstra** [00:10:05] Yes. Exactly.

**Carole Ann Alloway** [00:10:07] Oh, wow.

[00:10:08] I'm like, What do you mean there's nowhere to put it?

**Christa Haanstra** [00:10:11] Where's the whole section on patient preferences that should be there? That should be front and center.

**Diane Berardi** [00:10:16] Exactly.

[00:10:17] And another difficulty I have, which I'm sure you're familiar with is, the doctors don't call back.

[00:10:27] I just I called my mother's doctor. I'm waiting.... He's the gastroenterologist. We emailed him. We called him. They told us e-mail would be the best way. That didn't work. A week and a half. I called back and I say, Geeze. He hasn't responded. Maybe he didn't get it.

[00:10:44] "Oh, no. He always gets his e-mail."

[00:10:45] OK. I'm going to call him.

[00:10:48] "He's not here. I'll tell him to call you."

[00:10:50] And then he doesn't call back. And then you call back again, and say, Geez I didn't get that call back yet. And now I'm on two weeks and I'm thinking, Why can't someone call back? It's just it's terrible.

**Christa Haanstra** [00:11:04] Carole Ann, I know that you have stories about this.

**Carole Ann Alloway** [00:11:07] I sure do. In fact, with my husband's specialist... they never called back even to try and set up an appointment. So I ended up after months of waiting. I actually went down to the hospital and stood in front of her desk and made an appointment. And other caregivers would sit in the waiting room and say, well how do you get in touch with them?

[00:11:35] [Laughing] And we're sharing our tips and tricks out there.

**Diane Berardi** [00:11:39] And you know it's great that you did that. You had to be creative and you had to do what you had to do. But it's... You know at the same time it's sad that we have to do that.

**Carole Ann Alloway** [00:11:50] It is.

**Christa Haanstra** [00:11:51] Well, what if I had small kids at home, and I was working, and I was looking after my parents? And you had to do all this. Like if... That would just be overwhelming.

**Diane Berardi** [00:12:02] And there's so much that overwhelms us, now.

[00:12:06] Carole Ann, I saw the wish list on your Web site and it's fantastic. How did you come up with that?

**Carole Ann Alloway** [00:12:15] Thank you. Yeah. The wish list is on the change Foundation Web site.

[00:12:20] After navigating the health care system with my husband, for five years, through nine surgeries, I was diagnosed with depression. And that came as such a shock, because I think of myself as a pretty strong person. After all, I survived four teenagers. [laughing].

[00:12:39] So I had a small pity party for myself for a couple of days. But then I thought, what should have happened that would have made our lives easier? So I just started to write down at every stop along the way, What could have been done differently.

[00:12:56] And I had this three page list of things that could have happened that would have changed things for the better. I don't think we would have had nine surgeries. I don't think I would have gotten depression. He also developed heart problems and gastro issues because of this. So I think there was a lot of things that happened that's a result of this that wasn't even the original cause.

[00:13:24] So it's really a practical list for health care professionals of what could be done to make life easier for the family caregiver.

**Diane Berardi** [00:13:36] Oh definitely. Some of the things you had on that wish list, and the one that rings true... "I don't want to repeat my story, again."

[00:13:48] Oh my gosh... That happens. Well you can imagine through nine surgeries and the home care people and seeing different specialists and everything. We were telling our story all the time.

**Christa Haanstra** [00:14:00] I think that is the number one complaint, when we talk to caregivers across Ontario. That is the number one complaint. "I am so tired of repeating my story." And more importantly, what if I don't remember the most important part to the person I'm sitting in front of? Because I don't know. I'm not a healthcare professional. .

**Diane Berardi** [00:14:16] It is very stressful.

**Christa Haanstra** [00:14:18] Super stressful.

**Diane Berardi** [00:14:20] We are going to continue talking with Christa and Carole Ann from the Change Foundation. But first if you a woman, or there's a woman in your life, there's something you absolutely need to know.

[00:14:35] 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.

**Announcer** [00:16:36] You're listening to Parents Are Hard To Raise®. Now.... Thanks to you, The number one eldercare talk show on planet Earth.

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**Alexa** [00:17:05] Getting the latest episode of Parents Are Hard To Raise®. Here it is from my iHeart Radio.

**Announcer** [00:17:11] It's as simple as that.

**Diane Berardi** [00:17:13] 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 one hundred and eighty million listener is on Spotify. You can listen in your car, at the gym, or pretty much anywhere on your smartphone with Apple podcasts and Google podcasts.

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[00:17:58] Carole Ann, we were talking about your wish list. And one of the big problems here, which I noted on your list... Number one transportation, is is very difficult and it's costly. And I imagine you have the same problem.

**Carole Ann Alloway** [00:18:15] Yes absolutely. And driving my husband to.. Actually had appointments almost every day, either with the community care people or a specialist or a doctor. And getting him in and out that the car was a real challenge.

[00:18:31] I should mention that my husband is six-foot ten and I'm barely five foot two, on a good day. So... Managing him, getting him in and out of the car, giving him a bath and anything like that. Moving him around from a bed to a chair was always challenging. So yeah. Getting out, and it takes so long to get him out to the car, go to the specialist and then get him in the car and back home again. It takes a big chunk of your day. And parking is expensive around hospitals..

**Diane Berardi** [00:19:11] Yeah. I mean it used to be free to park in the hospitals here and then all of a sudden everybody's charging.

**Carole Ann Alloway** [00:19:18] Yeah. And it's expensive.

**Diane Berardi** [00:19:22] It is expensive.

[00:19:23] Another problem... Rehabilitation, People don't realize, it's a unique space, as you say, in the health care system.

**Carole Ann Alloway** [00:19:32] Yes absolutely.

[00:19:35] And whether you have it at home or you have to go out and have your rehab. There is a lot to think about with regard to that and whether or not the caregiver is going to be able to participate. Because sometimes they ask at home, when you have a caregiver at home, to help with the exercises and stuff. But there again, they don't consider whether or not the caregiver has a life of their own or they're capable of doing it. I could not lift Bill. The first time I gave him a bath, that was just such a disaster. [laughing]

[00:20:11] I can't imagine. Sure. And no one probably trained you on how to do it. Right?

**Carole Ann Alloway** [00:20:19] No no. No one ever... And you know, people look at us all the time and go, Wow look at that height difference. But no one ever said to us, Wow, how is she going to manage at home with him? Like he's on crutches and he has this leg in a

cast. And one time I was pushing him in a wheelchair, up a ramp to try and get in the wheelchair access door and I could barely push him up because he weighs like 220 pounds. And people were looking at us going oh my gosh look at that little woman trying to push him, but no one no one thought of well, maybe I could give them a hand. .

**Diane Berardi** [00:20:56] I know. I mean it's crazy. [laughing]

[00:21:06] Krista, I wanted to ask you... What difference are you seeing through the caregiver programs that you've been involved with?

**Christa Haanstra** [00:21:14] Yeah. So at the Change Foundation we've got four partnerships across Ontario where we've identified people and organizations that really understood this, the role of the caregiver and really wanted to work with them differently.

[00:21:27] So we've been working with them for about two years. And I think the biggest thing that we see is just that ownership of the caregiver role, so they feel proud of being a caregiver and they feel respected and valued when they're asked their opinion at the doctor's office. And they feel like they're entitled to ask for the education or the training or the information that they need in order to be successful at home. So you just sort of see this, instead of being a bit buried and weighed down by it, they embrace it a bit more and then also can be much more proactive in asking for what they need.

[00:22:13] And I think one of the things that we see a lot is that people don't say, Oh, my husband had a stroke yesterday, I woke up today and now I caregiver. It does it doesn't work like that. You know it takes weeks for people to think, Wait a second. Sure I'm his spouse. But now suddenly I'm in this role where I'm taking on much more of a caregiver role. And so, people don't think about what do I need to do differently as a caregiver? What do I need to ask for or what's available to support caregivers? But when we see these four programs happening in Ontario, where we're really empowering caregivers and partnering with them as real in the health care system, you see a different kind of interaction and a different kind of almost self advocacy and ownership of the role, but that allows them to get what they need.

[00:23:02] And so that's been really powerful and very emotional and moving for a lot of people involved in the programs.

**Diane Berardi** [00:23:09] And one big issue for all of us is to look after ourselves. You know realizing that that's just as important as taking care of your mom or dad.

**Carole Ann Alloway** [00:23:24] Absolutely. I would say that it's one of the most important things. It's not a nice to have it. And as a caregiver you shouldn't just think well I'll do it tomorrow and then tomorrow never comes. It's absolutely critical that you recharge your batteries every single day. Because you will get burned out. You'll get exhausted. And that's when mistakes happen. People get angry. They get depressed. You know it really takes a toll on you and emotional... It's not just the physical toll, it's the emotional and the spiritual. And the patient is being looked after. Because it they've got doctors and nurses and everybody around them, but the caregiver also needs support. And it's so important for the caregiver to recognize that in themselves and make sure that they get it.

**Diane Berardi** [00:24:18] I know it's funny. Like I said, I've been in health care you know 36 years and suddenly... And I'm really not a hands on caregiver for my mom and dad. I mean maybe twice a week I am. I do a lot for them, but I'm managing all their doctor

appointments. And we're taking them to the doctor. And I'm going shopping for them. And I'm helping my mom bathe. And you know, meals and just making sure all these things... Helping my dad pay bills. And I just keep going and going and going. And then I'm driving into my office today and I'm just... You know I'm feeling so sad. And I'm thinking well why am I sad? You know they're doing okay. And but it just... You need that emotional support. It just kind of hits. You you know they're in the hospital, if something happens, they fall and something happens. And you say okay, I'm helping them out. And you don't realize maybe how long it may be that you'll be doing this. Or suddenly maybe you do realize it, and you're saying, how am I going to do it? And I'm not quite sure what was going on in my head this morning when I'm driving there, you know. But I just felt so sad. And like you said, Carole, you fell into depression. And it just kind of happened. So we really do take care of ourselves.

**Carole Ann Alloway** [00:25:46] Yeah. And you don't ever see it coming.

[00:25:48] I didn't see it in myself. Other people saw it. I knew there was something wrong with me because I was either crying or angry. But other people saw it and made sure that I got some help. But it was after five years. That's a long time to go.

[00:26:07] So that with your parents, you know it's hard it was hard for me to ask for help and not ask my children because that just seemed wrong. It's usually us helping them. So you know I think for yourself it might be the role reversal that's challenging.

**Diane Berardi** [00:26:28] And I I think even though we know our parents are aging and they're not going to live forever and... But it felt like Oh my God. You know we just happens all of a sudden and then... It's like a moving train. Right?

**Christa Haanstra** [00:26:46] I think that we get very task oriented when we're caregiving and like you know you're talking about taking your parents to appointments and you're talking about you know making sure they get to the right place at the right time.

[00:26:57] But the opportunity to actually step back and realize that you know you've done this for three months and what is, what does the future hold? You know those are the moments I think it really hits us. And I certainly have that in my own caregiving experience where I care for my dad who has early onset dementia.

[00:27:16] And you know I can do all the things like show up the doctor's appointment. And I can be very organized. And ask the right questions. But it's often when I'm alone in a car that it sometimes hit me. Like, this is this is... My dad's never gonna be the same again. And this is the best it's going to be. And how do I make the most of it? And how do I manage the guilt of not spending enough time with him while he's still able to? And all of those pieces wear down on you. And I think the one thing I would say around Carole Ann's experience and what you were just talking about...

[00:27:52] Our research shows that people don't reach out for help as a caregiver until they burn out. And so, what we're seeing is a difference in the programs that we're implementing. Is that because health care professionals are being proactive in connecting with caregivers. And referring them to programs early on. They're also getting support earlier than they would have before. And that I think might be the biggest legacy of some of these programs that we're working on.

[00:28:20] I definitely think so. Yeah.

**Carole Ann Alloway** [00:28:23] Recognizing the role and respecting the role is also a big part of it, because you're not always fighting to be heard. Which is exhausting.

**Diane Berardi** [00:28:33] Yes it is. It is.

[00:28:36] Thank you so much. Carole Ann and Christa.

[00:28:40] Your Web site... Could you tell us your Web site?

**Christa Haanstra** [00:28:42] Yes it's ChangeFoundation.ca.

**Diane Berardi** [00:28:46] And I know you'll be back. We're going to have you back on future shows.

[00:28:52] Thank you so much for being here.

**Carole Ann Alloway** [00:28:52] Thank you. It's so great.

**Christa Haanstra** [00:28:54] Thank you so much for your interest.

**Diane Berardi** [00:28:57] Parents Are Hard To Raise® family, keep sending your e-mails and questions.

[00:29:01] You can reach me at Diane Parents Are Hard To Raise®.org or just click the green button on our home page.

[00:29:06] 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.

[00:29:13] Our New York producer is Joshua Green.

[00:29:17] Our Broadcast Engineer as Well Gambino.

[00:29:19] And from our London studios the melodic voice of our announcer, Miss Dolly D.

[00:29:23] We love our parents, but parents sure are hard to raise.

[00:29:27] Thank you so much for listening.

[00:29:29] Till next time... May you forget everything you don't want to remember, and remember everything you don't want to forget.

[00:29:35] See you again next week.