

Parents Are Hard To Raise S03 Episode 121 Transcript

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[00:00:37] Caregiving is a tough enough job. Caregiving for someone with mental illness and addiction... Well, that takes things to a whole new level.

[00:00:46] This week on Parents Are Hard To Raise Diane is joined by guest experts Marilyn Macaulay and Joanne Sidorchuk to discuss the unique challenges and solutions for those caring for the mentally ill and addicted.

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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] In the broad range of community health, helping family caregivers who are dealing with mental illness and addiction issues of a loved one tends to be either glazed over or silently swept under the rug. But thanks to an innovative partnership initiative between Ontario, Canada's Change Foundation and Cornwall Hospital that's all changing.

[00:01:52] My guest experts this week are Joanne Sidorchuk and Marilyn Macaulay. Joanne is the Director of Strategic Initiatives Community Programs at Cornwall Hospital and the embrace project co-lead. Marilyn is an entrepreneur, an experienced family caregiver and a noted advocate for patients and caregivers in the addiction and mental health system. Together they are part of it innovative team that is working to improve the experience of family caregivers in the addiction and mental health system across five districts in Ontario, Canada.

[00:02:27] Joanne, Marilyn, welcome to Parents Are Hard To Raise.

[00:02:32] Thank you so much Diane. We love your show and thanks for the invitation to be here.

[00:02:36] Thank you so much and I love to hear what you guys are doing. I think I'd like to start, if you could describe how and why the experience for caregivers of those with mental health illness is different than other caregivers.

Marilyn Macaulay [00:02:54] Yes there are some big differences. There is often stigma and judgment from society and from some health care providers, and many families choose social isolation due to shame and embarrassment. And another big difference is that there's no physical test for mental illness. So diagnosis is very slow and often takes five to 10 years or longer. And the faster any illness is diagnosed the greater the chances of a full recovery. So we lose a lot of valuable time waiting for a diagnosis. And untreated mental health issues result in loss of relationships and careers and self medication through alcohol and drugs and sometimes homelessness and suicide. And when a patient is physically ill they want to go to the hospital and they readily accept treatment. But that's

often not the case with a mental health issue. Patients can experience something called anosognosia and have little insight into the illness.

Diane Berardi [00:04:00] What is that?

Marilyn Macaulay [00:04:03] It's when a patient doesn't realize they are ill and the result of it is the denial of the problem, and treatment and medication noncompliance, which is frustrating for the caregivers.

Diane Berardi [00:04:16] Oh my gosh, yes.

Marilyn Macaulay [00:04:18] Yeah. And getting the person to a hospital can be difficult and sometimes involves the police. As a result we get the person to the hospital sometimes the caregivers are labeled as dysfunctional because of the chaos of the situation.

Diane Berardi [00:04:37] Do you find, I suppose caregivers, probably initially with a family member, maybe they're not sure what's going on. But they probably should, you know, go to their doctor inquire right away, when they first noticed signs of something being wrong.

Marilyn Macaulay [00:04:56] Yes, but often when there's something wrong the person is labeled as a behavior problem and things like that right away. And it sometimes takes a long time to diagnose the illness.

Diane Berardi [00:05:09] My gosh. What makes your population and your location unique?

Joanne Sidorchuk [00:05:16] Sure. And I'll definitely speak to that. So this position is unique because it's just so complex for these caregivers. I mean some of our kids, caregivers, who've been helping their loved ones and if not with not help their addiction challenges, some of the batch of young caregivers at really young ages perhaps from the age of eight or younger. So there are young carers who are, just like the title of your show love your show, you know, Parents Are Hard To Raise, some of these parents are being raised by really young children. And we call them young carers.

[00:05:48] So these children and young adults are caring they're growing up in an environment where they really don't know what it's like to not have to care for a parent. And sometimes they are seen as perhaps the problem themselves. And it's a really complex web for these family members who are trying to care for somebody. Right. As Marilyn was saying certainly often initially especially you know the "blame" in quotations is on the family members about how this this situation can arise. And you know it's just not like some other physical or medical issues that you see because no else can see it. And it's the stigma around it that if you hear your neighbors you know family member has an addiction or a lot of heartbreak albums. Sometimes people just stay away and they create the socialization as well.

Diane Berardi [00:06:43] You're right. You're right. People are afraid. They're fearful because they don't understand.

Joanne Sidorchuk [00:06:48] They are for sure. Yes. And also providers. So when families go to see their doctor, doctors don't always know to ask the questions or maybe

they don't want to open that big can of worms. And it's also a conversation that take a long long time.

[00:07:05] But our health care system isn't actually set up for that, to really be able to delve into helping not just the patient but the family supports for that patient.

Diane Berardi [00:07:14] So what does a family member do? What would be the first step if they feel there's something wrong? What would you suggest?

Joanne Sidorchuk [00:07:25] You know, I'm so happy you asked that because we've actually as part of our work, put together steps in order for family caregivers because they don't know where to go. And our first step is around telling someone. And that's a hard first step because you have stigma. And how do you know who to tell. You don't know how they're going to react as well. So we really encourage that you need to tell somebody that you trust about it. And and even just talking about it is a first step for sure.

Diane Berardi [00:07:55] I imagine if you're a child in school maybe you if you trust your teacher or your guidance counselor or someone like that who could direct you. But are teachers and guidance counselors for instance are they aware?

Joanne Sidorchuk [00:08:14] They're probably aware that there is something going on at home. You know they're probably aware that perhaps the students coming in late, not doing their homework, is perhaps a difficult student in the classroom. But are they aware of the impact of what's going on for that child when they leave the classroom and leave the school? Not very many are aware and that's kind of what we're trying to get out to the community is around really asking some of the questions and trying to know about those lines of conversation around these really difficult topics.

Diane Berardi [00:08:49] You know for a teacher maybe if if a child came to her, she would need to know where to direct that child. Right? So they have to be educated as well, the school systems, places of employment... Right? I would imagine.

Joanne Sidorchuk [00:09:04] Oh absolutely.

[00:09:06] And we really did hear that. And we heard also when we talked to for example staffing mercy department we hear her reasoning that they want to help caregivers but they really don't know how.

Diane Berardi [00:09:18] Yeah.

Joanne Sidorchuk [00:09:19] Yeah. So Marilyn will speak to a website that we created for not just our local caregivers but for all caregivers to help them know what to do. So maybe Marilyn can speak to how we created that Web site and what's on it.

Diane Berardi [00:09:33] Yeah. Perfect.

Marilyn Macaulay [00:09:34] Sure. We've interviewed 200 caregivers at the beginning of the project and most of them said they didn't know where to go or who to call. So we created a one stop shop called embracedcaregivers.com and it's got information about the caregiver journey, self care, local resources, caregiver skills. It's got a whole section for young carers because there's young children out there many parents who have addictions

and mental illness. And there's a section for providers and provider resources and helpful links on advocacy and resources and government benefits and all kinds of things.

[00:10:17] And one of great goals the Web site is we really want people to know that they're not alone. Their experience is not unique. When you look at the statistics just about mental illness alone, you know it's a very high incidence. You know I've heard the statistics, one in five people sometime in their lifetime could have a diagnosis that you know would align with a mental health illness of some kind. So you think about all the people it impacts, there's many many caregivers out there. And so people are not alone. I'm hearing a lot more people talking about this. I mean for sure it's because we're on the project but when I think every place I go when we start to tell people about what we're working on and the floodgates just open, and stories come out and people really want to talk and I have a lot of questions.

Diane Berardi [00:11:04] What kind of challenges did you need to overcome?

Marilyn Macaulay [00:11:11] One of the big challenges was where the privacy laws and consent laws.

Diane Berardi [00:11:16] OK.

Marilyn Macaulay [00:11:17] A lot of caregivers were not included in the circle of care. So we had to educate these health care providers on including caregivers and also the privacy laws do allow Inclusion of the caregivers and.... So. That type of thing.

[00:11:42] Joanne, I was looking at your background. You have such a diverse background, and I'm saying, now how... [laughing]. But you tell us how you got involved in this. I mean I could see where your background would be perfect for you to introduce solutions and be innovative in the healthcare system and come up with things. But tell us how did this all come about?

Joanne Sidorchuk [00:12:10] It's a great question, Diane. I would tell you, every morning I wake up and say, Wow I work in the system of Addiction and Mental Health. This is amazing. And I am a physiotherapist by training and you know being in health care field. We're all here because we want to help. Not just patients but caregivers as well and whoever we need to help the patient have the best care and the best outcome. So as a physiotherapist, it was really easy to find the caregivers, because I would in the hospital, I would go into a room there'd be a patient there with a leg in a cast and a family member be sitting beside them. And it was extremely easy conversation, there is no stigma. It was quite clear who needed to do what. And the caregivers were asking, What can I do to help?

Diane Berardi [00:12:56] Right.

Joanne Sidorchuk [00:12:57] And it's so it's fascinating what I am now working with and helping caregivers in the addiction mental health system. Poof they're gone. Where are they? Sometimes they can be very hard to find because often at times the relationships are very strained.

Diane Berardi [00:13:13] Yeah I would imagine.

Joanne Sidorchuk [00:13:15] So, the caregivers sometimes aren't really there.

Diane Berardi [00:13:17] Yeah. Do you see a lot of I guess doctors prescribing and you know leading to these addiction issues?

Joanne Sidorchuk [00:13:28] Yes absolutely. I think that's not unique at all to our area. I think you're right. We hear about the opioid crisis and what's going on. And so I think that's a... I'm glad you brought that up because it really speaks the stigma part that with addiction. Addiction can affect many people of all walks of life, of all levels of functioning, of all levels of income. And it can have a very profound effect. And it's a struggle to overcome an addiction. And I think the health care system has to really be careful about not placing blame and really coming at it from a point of helping and and knowing that there is a family out there as friends or there's a landlord or a neighbor.

[00:14:13] You know there's usually somebody who is available and can be a source of strength for that client or that patient.

Diane Berardi [00:14:23] You know you do worry about it. They have my mom on... They're trying all kinds of different drugs, and I'm like, Oh my gosh, you know. I'm so worried, you know, I'm like she's going to become addicted to these drugs. But you're in a crazy situation because you're trying to help with what's going on physically. So as a caregiver it's it's a struggle.

Joanne Sidorchuk [00:14:46] It is. And sometimes people who are on many kinds of drugs. It's called concurrent disorder where there could also be some mental health problems as well. And Marilyn if you want to speak a bit to some of the charges you've seen for caregivers who are helping somebody with concurrent and it's you know it's really this is where things get really complicated because we're dealing with many care providers in different buildings who don't communicate. The charts are different. You know what's causing what? Well if you are the addict asking about that.

Diane Berardi [00:15:21] Well we are going to continue talking with Joanne and Marilyn about mental illness and addiction issues and we'll talk about what you just said, when we come back [laughing]. But first, if you're a woman, or there's a woman in your life, there's something you absolutely need to know.

[00:15:40] 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 [00:18:09] Getting the latest episode of Parents Are Hard To Raise. Here it is from iHeart radio.

Announcer [00:18:14] It's as simple as that.

Diane Berardi [00:18:16] 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 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 could 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 where you want, when 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.

[00:18:59] So Marilyn, you were going to talk to us about concurrent issues for patients and addiction.

Marilyn Macaulay [00:19:07] Yes a lot of people with mental health issues have Addiction issues also. So the system even gets more complex to navigate. And often those caregivers need extra help. And they also need help in knowing what to do while they're waiting to see health care professionals.

Diane Berardi [00:19:26] Yeah. What do they do?

Marilyn Macaulay [00:19:28] There's long wait periods and it's often good to refer the caregivers to support groups at that point so they can see that they're not alone. And they

can get tips on how to cope with the situation. And there's a good caregiver education programs out there. So as long as the the health care professionals are referring them to the resources they can get through the work waiting periods.

Diane Berardi [00:19:57] And with your background, what's it been like for you being part of this team?

Marilyn Macaulay [00:20:04] Oh it's been wonderful. I have been a caregiver to someone with a mental health issue for 18 years and so I have done a lot of advocating both for my family member and for other caregivers.

[00:20:20] And it was like I was retired and had no plans to go back to work and when this opportunity came up it was like a dream come true for me.

Diane Berardi [00:20:31] Now you said you've been a caregiver for 18 years. When the illness first presented itself, How did you know what to do?

Marilyn Macaulay [00:20:41] I didn't know what to do. Yeah we ended up at emergency and that was the starting point for us. And it took a while to get diagnosed. And we tried all different things. And. Finally I took my family member to actually another province and got the help that he needed and deserved. And he is actually doing very well today.

Diane Berardi [00:21:11] Oh that's so great to hear. That really is. And you are an advocate for family caregivers making sure that you know they are partners in this whole process.

Marilyn Macaulay [00:21:24] That's right. That's right. The patient's chances of recovery go up a lot if the family is included. So I'm always looking at that aspect of care of trying to get families to advocate and trying to get them included in the treatment decisions.

Joanne Sidorchuk [00:21:43] Well you know, Diane, yeah we really chuckle around here because we look at the Web site and Marilyn was so so instrumental in working with the other caregivers to put the website together, but we laugh and we say that it's really a combination of her entire home office on our Web site. Because she's spent so much time having to research on her own. Now we'll come in and start telling us about new blood tests for various mental health illnesses that the doctors don't know about. Because the families have to really spend time digging in and researching themselves and advocating and pushing for the kind of care as you heard Marilyn say, for their loved one.

Diane Berardi [00:22:22] There's no better advocate, you know I believe, then a family member.

Marilyn Macaulay [00:22:27] That's right.

Diane Berardi [00:22:28] Really. Because you know that's our loved one. But it can be frustrating for us. So these programs are vital.

[00:22:38] Joanne, what are your hopes for the future of the program?

Joanne Sidorchuk [00:22:43] You know there's just so many different avenues that we could go down. It's completely endless and there's so many collaborations with other organizations nearby and far away that it's really this is just so exciting what we can do for

sure. Well we really hope is that others follow in their footsteps and start to talk about how they can better include caregivers. And how... And it's not that hard. No we hopefully on our Web site embrace caregivers dot com. We have all of our tools that are completely shareable and they adopt them as people like. And we really encourage that people work with caregivers, because I look at the outcome of what we've been doing we wouldn't be half as far as we are if we didn't have caregivers with us. And we also would be come at this from an angle that you know traditionally is from our angle. Ya know, we're going to design something, implement it without including caregivers in the implementation and the outcome isn't as good as it could be.

Diane Berardi [00:23:43] Oh definitely because, I think about all my years in health care, but now being a caregiver, how so important it is for my input when my mom goes to a doctor or for a test or to the pharmacy because you don't realize how... We're their voice.

Joanne Sidorchuk [00:24:05] Yeah. And with this population I think even more so. A big takeaway for me having come from working in a true sort of medical field to addiction mental health is what Marilyn told me right from the beginning, and I didn't fully believe it but her power through it really ingrained in it, that the caregivers are truly experts in the care, because especially addiction mental health they see their loved one at home and all kinds of environments and they see the roller coaster of the journey they're on, ups and downs and they and they can get into sort of the thinking of their family member more so than can happen in a short clinical or emergency visit.

Diane Berardi [00:24:45] Right.

Joanne Sidorchuk [00:24:45] So truly these caregivers they are the experts in the care.

Diane Berardi [00:24:49] And I imagine a physician, you know you come in and you're talking about what you've been noticing, and they look at you sometimes probably and think, Well I don't see that. You know, I'm not seeing these signs presented.

Marilyn Macaulay [00:25:03] That's right. Yeah.

Diane Berardi [00:25:05] Well how can our Parents are Hard to Raise family help? What can we do?

Joanne Sidorchuk [00:25:11] Well that's a great question. First of all I would say for anybody out there who kind of resonates with what our message that's there, if they're not part of a support group, if they don't know how to self help, if they're feeling burnt out, stressed themselves, number one is to talk to somebody. So if they can find a friend family member, anybody trusted would be really important. Anybody who can... Speaking to the providers, anybody in the addiction or health care system to really advocate and ask about how can a family be included. For example, even taking their member to an appointment instead of away in the waiting room they ask is, Can I come in? You know it's not always appropriate and the time is not always right, but maybe to ask the counselor a therapist, When it's a good time for me to be there as well?

Diane Berardi [00:25:59] Yeah.

Marilyn Macaulay [00:26:01] And I think another thing is to try to get consent from the patient so you can give information to the family caregivers. And also to educate the caregivers because it's not easy work, Living with an addiction or a mental health issue.

And the patients really need supportive families. And some families don't know how to do that and need to be educated.

Diane Berardi [00:26:23] No you're right. That's exactly right. Some families really don't... You know they don't know what to do.

Marilyn Macaulay [00:26:29] That's right.

Diane Berardi [00:26:30] We have a large worldwide audience of health care professionals who are listening... How can they help you?

Joanne Sidorchuk [00:26:41] It's just it's just it's a phenomenal prospect around connecting certainly through our EmbraceCaregivers.com website. People can connect with us. They can share not just what is on the Web site but through our learnings. We have a lot of learnings around including caregivers and code design and leading these projects that involve a complicated health care system. And certainly we love to hear ideas of what others are doing as well. We can certainly not ourselves but there's so many pockets of work right now happening in this area that we would love to hear about what's happening and some of the successes that, and some of the things that maybe didn't go so great for other providers and their organizations who are trying to work on this.

Marilyn Macaulay [00:27:31] One of the things that we're going to do at our hospital is to put in and our caregiver center, so caregivers who need information, need resources, or need support can come to our caregiver center and get that support or just sit and relax and have a coffee. And We have documentation like the rights of the family caregiver. We have a discharge checklist that the caregivers can take up to the mental health floor. And all kinds of resources and tools to help caregivers.

Joanne Sidorchuk [00:28:09] Marilyn, you mentioned the rights of the family caregiver. We had a focus group recently and when we mentioned the rights of the family caregiver, that came out loud and clear to us. Caregivers want to see those rights spread. In our organization we certainly have rights for patients, but picking up on rights of family caregivers because caregivers don't realize that they do have a right and they don't understand how they can become partners.

[00:28:35] So having something as simple as a poster up in an organization's entryway or in our unit is very helpful to help caregivers realize... First of all, help them realize they are caregivers. And how they relate to it. And also they do have rights that will encourage them to want to get more involved and ask questions.

Diane Berardi [00:28:56] You guys are doing such wonderful, wonderful work.

[00:28:59] Joanne and Marilyn thank you so much for being here.

[00:29:03] And thank you so much Diane. We love you there.

Diane Berardi [00:29:07] Oh you're welcome.

[00:29:08] Parents Are Hard To Raise family we love getting your e-mails and questions, so please keep sending them. You can reach me at Diane Parents Are Hard To Raise dot org or just click the green button on our home page.

[00:29:18] 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.

[00:29:26] Our New York producer is Joshua Green. Our broadcast engineer is Well Gambino. And from our London studios, the melodic voice of our announcer, Miss Dolly D.

[00:29:35] We love our parents the parents sure are hard to raise.

[00:29:39] Thank you so much for listening. Till next time... May you forget everything you don't want to remember and remember everything you don't want to forget.

[00:29:47] See you again next week.