

Parents Are Hard To Raise S03 Episode 94 Transcript

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[00:00:23] Coming up this week on Parents Are Hard To Raise®, Dr. Jennifer Olson, executive director of the Rosalynn Carter Institute for Caregiving is here to share some of the amazing resources they offer for family caregivers like us. Join 180 million monthly subscribers who can now listen to parents are hard to raise on Spotify.

Diane Berardi: [00:01:11] Welcome to Parents Are Hard To Raise® ... Helping families grow older together without losing their minds. I'm elder care expert, Diane Berardi.

[00:01:21] In America today, more than 50 million family caregivers provide care for their aging parents as well as for adults and children with disabilities and chronic illnesses. Add to that the vast number of newly returning service members and veterans and their family caregivers who are struggling with the challenges of their injuries, both physical and emotional, and you can see the makings of a real public health crisis. That's where the Rosalynn Carter Institute for Caregiving comes in.

[00:01:53] The Institute is part of Georgia Southwestern State University. It was established in 1987 in honor of former first lady Rosalyn Carter herself a family caregiver a GSW alumna and who serves as president of the Institute's board of advisors. The institute provides education, training, resources, research and community based programs to help support and strengthen family and professional caregivers. Joining us this week is the Institute's executive director, Dr. Jennifer Olsen.

[00:02:28] Doctor Olsen is a globally recognized expert in epidemiology with a list of credentials so long it would take the rest of the show just to list them. So I'll give you the Cliff Notes.

[00:02:40] She holds degrees from Rutgers University, the George Washington University and the University of North Carolina. In addition to her extensive work with the United States government, helping to keep the rest of us safe from harm, she has worked with public health organizations and governments around the world. She spends her time as an advisor to the National Academy of Medicine and is a TED MED research scholar searching out experts involved in cutting edge research projects, to bring them to the TED MED stage.

[00:03:12] The first question I'm going to be asking her is, when did she find time to sleep? Jennifer, welcome to Parents Are Hard To Raise®.

Dr. Jennifer Olsen: [00:03:22] Thank you for having me.

Diane Berardi: [00:03:24] I'm so excited to have you as a guest to speak to us about this wonderful organization the Rosalyn Carter Institute for Caregiving. So, can you tell us what your organization does.

Dr. Jennifer Olsen: [00:03:37] So as you mentioned we started 31 years ago when Mrs. Carter left the White House and during the time of her campaigning for with President Carter and even before that she had constantly heard of the need and the challenges of caregivers whether it was the disabled child, a relative with a mental health condition, a loved one.. And realized that this was a category of work that no one had put a kind of focus towards.

Diane Berardi: [00:04:10] Right.

Dr. Jennifer Olsen: [00:04:12] And so some people referred to her as "the first lady of caregiving" and we see that as an indicator of her pioneering role in this work.

Diane Berardi: [00:04:22] Yeah.

Dr. Jennifer Olsen: [00:04:23] She has led us in taking different approaches to bringing research right out of medical journals into a practical approaches, so that family caregivers can learn from and build their own skills in caregiving. We say here that nobody went to school to be a caregiver.

Diane Berardi: [00:04:46] You're right.

Dr. Jennifer Olsen: [00:04:47] You know, you didn't... You don't learn that somewhere in your growing up or in your degrees; you learn it often on the job. And you learn it kind of as you're suddenly dropped in and a lot of circumstances to that role. So we've been working over this time to build programs and training to help people as they learn those new skills.

Diane Berardi: [00:05:13] Yeah. You know it's so true, family caregivers they received little training on how to deliver care. I can't tell you how many people say, My mom's coming out of the hospital and I... No one told me what to do. I don't know what to do. And they are... A lot of times they're not even treated as a partner in the care or encouraged to be able to learn or train. And so many of them want to learn and want to know what to do.

Dr. Jennifer Olsen: [00:05:39] That's right. And even when the caregiver gets some education, it's often about maybe the physical aspects of providing that care. But it isn't about the caregiver taking care of themselves or recognizing the challenges they're personally going to deal with.

Diane Berardi: [00:05:55] Yeah they don't know... Because it's like, "OK I'm going to take care Mom. She's coming out of the hospital." And they don't realize... yeah, the toll it can take on someone, unless they take care of themselves.

Dr. Jennifer Olsen: [00:06:08] That's right. So we've been looking at all of the mental and physical health challenges that caregivers experience as a result of this... This new role that they take on, sometimes for years or decades at a time.

Diane Berardi: [00:06:22] Right.

Dr. Jennifer Olsen: [00:06:23] And thinking about, you know, is there a... Is in some ways caregiving kind of a risk factor that if it means that you're more likely to experience diabetes or sleep deprivation or depression? And if so, when you go into the doctor the doctor doesn't say to you, Are you taking care of someone at home?

Diane Berardi: [00:06:44] Right.

Dr. Jennifer Olsen: [00:06:45] You know, are you... Let me ask you about your personal circumstance which might put you at risk for some health issues. So trying to engage caregivers in educating about their own role and what they can do to stay as healthy and as well as possible over those many years.

Diane Berardi: [00:07:06] And your organization supports both professional and family

caregivers.

Dr. Jennifer Olsen: [00:07:13] That's right. I think a bulk of the conversations are to... and training that we've come up with is to help professionals who are in that caregiving role recognize like not only that they're interacting with a patient but they're interacting with a caregiver, and the caregiver needs some love and attention as well.

Diane Berardi: [00:07:35] Right. Yeah. I had told a story on one of our shows about a daughter wheeling in her mom into a doctor's office and she, you can tell that she's tired and depressed and she's not taking care of herself and no one even notices her. You know? And you see that very often.

Dr. Jennifer Olsen: [00:07:57] And I think that's just a challenge of awareness in a lot of ways that we notice this especially with our veteran caregivers. They say that the veteran will often get kind of an indication; a Thank you for your service or How are you doing? And the caregiver will be sitting right next to them and they're there serving as well, but in a different way.

[00:08:23] So how to engage people around knowing that population exists.

Diane Berardi: [00:08:29] And that's so important, that really is. And the awareness... Letting everyone know, letting the public know.

[00:08:36] My mom was just recently diagnosed with pancreatic cancer and I have recently become, and really just a part time caregiver.

[00:08:50] You know, my dad is there with her and I'm just... I Mean I'm talking to her, you know, numerous times a day, and she's about two hours away from me and I'm up there at least twice a week. She has to go for chemo, etc. And it's not only that you're tired, you know, because you're still... You're doing your job. You have to go to work; there's so many people who have jobs and they're their parents maybe don't live nearby. And then the emotional toll. You don't realize what people go through.

Dr. Jennifer Olsen: [00:09:23] And I think that the challenges are growing. So I think it's around 60 percent of family caregivers are also working. And that's both working near their loved one or having to travel a distance or having to do distance caregiving; trying to contact doctors or set up care when you're states away.

Diane Berardi: [00:09:45] Oh, Gosh.

Dr. Jennifer Olsen: [00:09:45] Which is every I think there's different kinds of challenges that are coming into the caregivers space. And we always think of I think people get a mental image of a caregiver as a... As you know older woman maybe brushing an older man's hair. It's a very kind of traditional image. But caregiving is changing. And caregivers... Caregivers everybody you look around there in some ways potentially caregiving but you don't know because it's in their own home.

Diane Berardi: [00:10:15] Right.

Dr. Jennifer Olsen: [00:10:15] As part of their part of their day.

Diane Berardi: [00:10:18] Now, does the Institute specialize in particular areas of caregiving?

Dr. Jennifer Olsen: [00:10:24] So we currently have two major focus areas.

[00:10:28] The first is Alzheimer's and dementia caregiving, with again and attention on that caregivers well-being and self-care.

Diane Berardi: [00:10:36] Yeah.

Dr. Jennifer Olsen: [00:10:37] And the second is veterans and military caregivers; where we're working to help a whole caregiver family. So a small child who is helping out with some caregiving because their parent or relative came home from military with different types of injuries requires kind of a delicate approach to a new... You know you go to school as a small child and you come home and you have to worry about your mom or dad how they're doing that day.

[00:11:11] So I think we we have those two areas of focus which has come out of kind of our constant evolution towards what are what are the big areas where we can work. We've had previous focus on cancer caregivers on rural caregivers in rural settings because there are some different challenges there about isolation and lack of resources or distance to resources. And some about work on multigenerational caregivers. So if you're caring for both a parent and a child at the same time.

Diane Berardi: [00:11:44] Yeah.

Dr. Jennifer Olsen: [00:11:46] So you have plenty of areas of need as we as we look in this space and continue to see what's coming.

Diane Berardi: [00:11:53] Yeah. My gosh. You know you don't even realize the example you said, a child with a parent coming home from the military; you know coming home from Afghanistan. It's things that we're not even thinking about.

Dr. Jennifer Olsen: [00:12:08] Yeah I heard... I was speaking to a family and they spoke about how their child will recognize when they go to a restaurant where the parent has to sit because of their need to see a doorway or see an entry way. And it made me think about how our everyday activities are so different when you're a caregiver. I heard your description of bringing your mom to Bed, Bath and Beyond.

Diane Berardi: [00:12:34] [laughing] Yes.

Dr. Jennifer Olsen: [00:12:37] And it just further reinforced that idea of like everything... Everything that you think of is as a simple-ish task.

Diane Berardi: [00:12:44] Yes.

Dr. Jennifer Olsen: [00:12:46] If you're caregiving has had a lot of other complications. And you have to be kind of planning for A, B and C. And that means maybe you don't remember to to eat your lunch or to you know take your medicine or to do anything. Yeah.

[00:13:01] Yeah. You're right. Oh my gosh. I know, there's things you just don't even think about.

Dr. Jennifer Olsen: [00:13:08] That's right. So We have been working toward this for some time.

[00:13:12] We're going to continue talking to Dr. Jennifer Olson, executive director of the Rosalyn Carter Institute for Caregiving. But first, I want to tell you something. If you're a woman or there's a

woman in your life there's something you absolutely need to know.

[00:13:28] 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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Announcer: [00:16:03] It's as simple as that.

[00:16:06] 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 on one of these new ways, please do me a big favor. Please share this new technology. Helps someone else learn about the show and show them a new way to listen.

[00:16:53] Jennifer, I wanted to let you tell our listeners about the different programs at the Roslyn Carter Institute for Caregiving.

Dr. Jennifer Olsen: [00:17:02] Sure. One of our primary programs is "Operation Family Caregiver" which is a program geared towards military and veteran families including Guard and Reserve families and caregivers, so that they can build skills related to problem solving, over a six like a six session coaching. We do this because it's not as though there is a very specific set formula for what a caregiver is going to go through or what kinds of skills they need to build. They need to be able to kind of constantly adapt with their care recipient and with their family. And so we have built this program which has shown proven reductions in depression and physical health issues in the caregivers as well as reduced anxiety in the children in the household. And so we're really excited about the approach and think it actually could apply to a number of other caregiver types as people are taking on caregiving in a more family way as they need to. So that program has been around for I think four years now and we are expanding it to be on site at some of the Veteran Administration buildings across the country.

Diane Berardi: [00:18:21] Oh that's fantastic.

Dr. Jennifer Olsen: [00:18:24] The second major category of work we do, a programmatic work, is dealing with dementia. This is a program very much as I said about communication styles and approaches, ways to engage with your care recipient; your loved one as a caregiver. As well as aspects of self care and approaches to recognizing your role in that caregiver role that you've taken on. And this we have an extensive guide and a training class, a set of training classes that goes with that.

[00:19:00] What we've learned is that much like any other kind of class you go to you can listen you could listen and it would be you pay attention to some parts and you wouldn't to others. So we worked on building tips and additional items that somebody can look at when they realize, Oh... I should have paid attention to those parts. [laughing] As any adult you know they're of kind of there in their distracted world. So we're continuing to evolve that.

[00:19:31] And we have another program for Alzheimer's and dementia caregivers which is called Reach. And I think of that a little bit as couples counseling.

[00:19:43] It's helping both the caregiver and the care recipient to work together in their new their new normal.

Diane Berardi: [00:19:50] Now that's great.

Dr. Jennifer Olsen: [00:19:51] Yeah. 'Cause, I think that we... We make it seem, we kind of give a caregiver a bunch of training and we say, You just go home and do this. This will work.

Diane Berardi: [00:20:02] Right. [laughing]

Dr. Jennifer Olsen: [00:20:02] But I think by having somebody in that kind of counselor coaching that's talking to both parties they can understand the challenges a little bit better and help both sides in whatever their struggles are.

Diane Berardi: [00:20:18] Yeah. Yeah, that's wonderful. It's true because you can give all this advice and say, OK... Yes that's what you have to do. But you know then you have their partner...

Dr. Jennifer Olsen: [00:20:31] That's right. That's right.

[00:20:34] We also have a program called... with the Benjamin Rose Institute... Care Consultation Program, which is provided in Georgia where we're based, as a way for people to go through a very intensive approach to safety and well-being for their care recipient and to kind of go through what services might be needed; to help with navigation for that caregiver and that care recipient. I mean that program goes over the course of a year. So that's pretty extensive and unusual in that regard.

[00:21:09] And then our last is a a set of modules called "Caring for You and Caring for Me," Which is just kind of a broad any kind of caregiver needs some help with that, Self care; that recognition of their own well-being and how it's being impacted. Just even some recognition of changes in their emotions or their temper because of the added burdens that the caregiver is taking on.

[00:21:37] So... And we're kind of thinking now about how do we move some of this content to more and different formats. So as our caregivers are changing in age or their comfort with whether it be technology, or their desire for smaller sessions. You know people don't want to sit for a two hour class. anymore...

Diane Berardi: [00:21:59] Right. OK.

Dr. Jennifer Olsen: [00:22:02] How do we... How do we package things into more bite sized pieces, but still make them valuable.

Diane Berardi: [00:22:09] Yeah, that is a real challenge with an older person who isn't tech savvy, that is a caregiver.

Dr. Jennifer Olsen: [00:22:16] That's right. And Most of that caregiving kind of technology and apps are based on helping a caregiver kind of do the tasks of caregiving.

[00:22:25] And so we're trying to recognize that people need to learn how to do the tasks of being a caregiver while also learning that they are in a new... A new role. And it means different things.

Diane Berardi: [00:22:39] Yeah. That's the whole thing. You know it is it's. And many times the role is it just comes out of nowhere. We say that all the time it does.

Dr. Jennifer Olsen: [00:22:49] That's right. And we and we realize that people now may be... You might be a caregiver and then there might be a circumstance that changes and then five or ten years later you might be a caregiver for a different circumstance.

Diane Berardi: [00:23:03] Right.

Dr. Jennifer Olsen: [00:23:04] So it's not a one time experience. We also think about this with our, especially some of the younger a veteran caregiver families, that those individuals might be a caregiver for decades of time and so... And so the challenges and approaches are very much like, "Oh here's some skills you can build." As if it's you know they're on a short term journey. It's not the same.

Diane Berardi: [00:23:30] Yeah. I have clients who have a parent with dementia. And it's been

seven years, eight years and it's a long time. And then that parent passes away and then their other parent has an illness you know. So they're just being beat. It's just one after another. It's amazing.

[00:23:51] I look at people and I say, my gosh people are strong. You say, OK you can do this, and they are doing it. But we don't realize all the ramifications of it. You know, what happens to them.

[00:24:05] I know with my mom, I was just going to the hospital, she was admitted to the hospital, you know taking her to the doctor. I don't know if you heard...

[00:24:14] You Know she had had a cold. And then I said to her, You have to go to the doctor. And she had to be going out, because she had this cold. And she kept saying, I can't get rid of it. And I said, Ma you have to go to the doctor. And then she went to the doctor and she said, Oh the doctor took bloodwork. And the doctor says I'm jaundice. And I'm like, You're jaundice? And so she said, Yeah and then I have to go for an ultrasound and then I have to go back to the doctor. And I said to her, Well I'm going to come with you. You know... take you to that next doctor's appointment.

[00:24:45] And so when I went up and she answered the door, I mean she was yellow. [laughing] And I said, Mom, you're yellow! Am I?

[00:24:57] And my dad is there and I go, Dad she's yellow! Is she?

[00:25:03] And I'm saying, oh my gosh.

[00:25:05] And just from running back and forth and then she went into the hospital and they had to put a stent in the common bile duct and then she was back in the hospital for a biopsy and... I got sick. I just caught this cold. And I think it took three weeks and it finally went away. And then, bam, it just came back. So you don't realize the toll it's taking on you.

Dr. Jennifer Olsen: [00:25:27] We've been talking about this idea that a caregiver probably, like isn't going for their flu shot or any of those preventive things they're supposed to do. They're not they're not maybe refilling their medication like they're supposed to. Eating as well as they're supposed to. And so we think about all these like health behaviors the things you know you're not supposed to do. You're not supposed to have that that cheeseburger or fried chicken, but you do and you realize, Oh this wasn't the smartest choice. But we don't think about caregiving like that that like this is a every day you're... You're doing things that are going to impact your own health.

[00:26:07] And so that's one of the areas that in my now fourth month here I think about a lot, which is... That there are population level changes that we can think about to engage and recognize this is a public health problem not a individual in your own household problem.

Diane Berardi: [00:26:24] Right. Right.

[00:26:26] What needs do you anticipate caregivers will have in the future?

Dr. Jennifer Olsen: [00:26:31] I think there's a category around the fact that we have still a every kind of traditional family view of caregiving.

Diane Berardi: [00:26:40] Yeah.

Dr. Jennifer Olsen: [00:26:40] That it's that it's often the daughter or a spouse. But as families change and caregivers and care recipients move farther their other family approaches or other friend approaches that are needed for caregivers. And I don't know that our society has kind of recognized

that a caregiver isn't always going to look like or be that this relative. And so are kind of approach to, "Oh you'll just feel to take care of your mom or dad because that's what you're supposed to do."

Diane Berardi: [00:27:13] Yeah.

Dr. Jennifer Olsen: [00:27:14] It is going to is going to evolve. Which means that there are many people who will be kind of silent caregivers in the future. Because we'll be like, Oh this is weird I'm not going to talk about the fact that I'm taking care of my ex mother-in-law. Right? Like I mean these are reality.

Diane Berardi: [00:27:31] Yes. It's reality.

Dr. Jennifer Olsen: [00:27:32] And so part of I think the biggest issue that we look at is that caregivers... The numbers growing and the challenges are growing. But it seems like we're not doing very much to elevate the recognition for the caregiver.

[00:27:48] And I always think about this... When a friend has a baby or has a has an exciting life event or has a rough life event, you kind of have a playbook in your mind of culturally what you're supposed to do.

Diane Berardi: [00:28:04] Right.

Dr. Jennifer Olsen: [00:28:06] But when somebody says to you that they're a caregiver...

Diane Berardi: [00:28:08] Yeah.

Dr. Jennifer Olsen: [00:28:09] ... We All just kind of are like, Oh that's tough. And then... What, what am I supposed to do? Uhhh...

[00:28:14] Right Yeah you're right.

[00:28:17] I don't send the flowers. I don't know what to talk to you. You seem like you can never talk anymore. What do I... What, what's my position here? How do I engage? And I'm worried about that from a societal standpoint.

[00:28:33] Yeah you're absolutely right.

[00:28:35] I'm getting a signal here. We're running out of time. Jennifer, would you come back? Because I'm sure there is so much more we can talk about. We would love to have you back.

Dr. Jennifer Olsen: [00:28:47] I would love to. As I said, it's only month four, so I will learn. I.

[00:28:52] That's wonderful. Thank you so much for being here. I hope you got something out of this episode... Episode 94. I know I did.

[00:29:02] I love getting your e-mails and questions so please keep sending them.

[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. Our broadcast engineer is Well Gambino and from our London studios, the melodic voice of our announcer, "Miss Dolly D."

[00:29:24] Thank you so much for listening.

[00:29:26] Jennifer, how do people find out about the different programs at the Roslyn Carter Institute for Caregiving?

Dr. Jennifer Olsen: [00:29:32] RosalynnCarter.org. Our website lists everything we do.

Diane Berardi: [00:29:37] Perfect, thank you so much.

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

[00:29:45] See you again next week.