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## Proem 00:52

I'm worried that I'll never be able to hug my kids and my grandkids ever again. I'm a toucher and a hugger. When I saw my old friend, Jerry, several months ago, he kept touching me. 'We've known each other for a long time, haven't we?' 'Yes, Jerry, 51 years. It's a long time, isn't it?' Over and over, maybe 51 times in two hours. I loved every touch. I love every hug. Sigh...

I first introduced my finance to my other mother, Eleanor, in Highland Park, Illinois, where I had grown up. Eleanor was mom to my best friend, John. We've been friends since we were in third grade. I noticed something was wrong, really wrong. While visiting, Eleanor kept repeating the same line and asking the same question over and over. She put her keys in the fridge - early-onset Alzheimer's. In nursing school, I took care of several people with dementia. I listened to family stories about going out to dinner, to the grocery store, and the doctors' offices with their family member with dementia. Sometimes the stories were slapstick humorous and always tragic. You might have heard my November 10<sup>th</sup> podcast episode, [Caring for Parents. It's Their Life. Open the Door](#) about my Keeney friends, Jerry, Jenni, and Becky. Jerry lives in a Memory Unit in Colorado. My friend Tania Marien, a fellow podcaster who creates [Talaterra](#), told me that her home, Riverside, California, is a Dementia-Friendly City. Intriguing. When I contacted the city, the Mayor's office referred me to Jill Johnson-Young and Stephanie Oden.

## Introducing Jill Johnson-Young 03:05

Jill is a social worker, LCSW. Her specialties are grief and loss, dementia, and death and dying. Jill has a private practice and does a lot of community education for community members and professionals. She finds that much of her community doesn't know a thing about dementia. Between the time I spoke with Jill Johnson-Young and Stephanie Oden, the coronavirus pandemic struck. Of course, COVID19 became

part of the story. Today we'll start with dementia and a Dementia-Friendly City with Jill Johnson-Young. Next week we'll hear from Stephanie Oden about managing a Memory Care Unit in the COVID19 pandemic and from Jennifer Keeney about her dad, Jerry, living in a Memory Unit today. Please join Jill and me as we talk about dementia and grief

Dementia – Ongoing Grief for all 04:03

**Health Hats:** It took me quite a long time to realize that part of illness is grief, whether dying is involved or not. It's the grief of what we were.

**Jill Johnson-Young:** And what we're losing every day. With dementia, it's ongoing grief for both the person who has dementia and for the family surrounding them.

**Health Hats:** That's an interesting statement. I haven't thought much about what it's like for the person with dementia, experiencing their own cognitive changes. Can you say more about that?

**Jill Johnson-Young:** There are so many kinds of dementias. Usually, when people think of dementia, they go right to Alzheimer's—depending on who you're asking, between seven or 12 or 17 different kinds of dementia. Everybody's process is different. Typically, the person who's realizing that cognitively they are changing will wait two years before they say anything to anyone. They will spend that two years desperately trying not to make it real and not let it be real. And then, depending on the kind of dementia, they may be seeing that they do not remember things. They're getting lost sometimes in their own house. They're experiencing people saying insensitive stuff to them that they don't mean to be inconsiderate. There's always somebody who says to you, 'Do you remember who I am?' Alright. Why would you do that? Why would you ever just put someone in that situation?

There is a man named [Norm Mack](#), who is surviving right now, although he is declining consistently with [Lewy Body Dementia](#). My second wife died of Lewy Body Dementia. Lewy Body's interesting because you lose memory, and then you come back, you become psychotic, and then you come back, and you remember where you were. So, you're fully aware of what's happening when you come back in. That's what Robin Williams had, and that's why he made the decision that he did. With Norm, you can hear somebody describing what it's like not to recognize someone you know that you're supposed to recognize. It's frightening. It's sad. It's frightening. It's frustrating.

**Health Hats:** Terrifying.

**Jill Johnson-Young:** I think it's everybody's worst nightmare even if they're not going to describe it. When I'm doing grief stuff, and I'm doing presentations, I'll say, 'how does everybody here want to die?' And what does everybody say? 'Oh, I want just not to wake up.' And that's not what happens with our dementia folks. So, with Dementia-Friendly Cities, we're trying to make sure that while they're having those losses, that the community's not inflicting more on them by making it impossible for them to go out for a meal or go to the ER safely, or those sorts of things.

Becoming a Dementia-Friendly City 07:27

**Health Hats:** Say more about Dementia-Friendly City. What is it? How did it develop?

**Jill Johnson-Young:** It comes from Europe. England took the lead in looking at what dementia was going to do worldwide when the G8 was still the G8. They stepped up and said, 'we're going to look at how to handle this.' Europe is far ahead of us in terms of how each country's handling it. They have a bit of an up on us because they're smaller countries. We're huge compared to most of them. They created Dementia-Friendly villages. Those villages are trained so that the grocer, the postman, and the neighbors all know that Mrs. so-and-so or Mr. so-and-so has dementia. They look out for them to make sure they're not wandering. They help them in the grocery store when the ATM doesn't make sense. They don't ask them the questions that they shouldn't ask.

The paramedics and fire folks know that they're dealing with someone with dementia and treat them differently because of it - with great respect. The Dementia-Friendly Cities came on board so that each community could decide that they want to present themselves as dementia-friendly. In Riverside, it got started because our Mayor, Rusty Bailey, lost his mom to dementia. He was particularly sensitive to it, and he knew how many places he'd run into things where people didn't understand what they were seeing. We got started because there was a man named Rich Gardner whose wife had early-onset Alzheimer's. Early-onset is the fastest-growing dementia along with mixed dementia. That means you're under 65, and you usually have about five years or less of a lifespan, no matter what dementia it is. I was his wife's hospice social worker at the time, so we connected. He was very aware of how isolated he was; how little support there was; how few people knew what dementia was; how hard it was to get Debbie out in the community and not have her feel awkward and scared. So, he got in touch with the Dementia-Friendly Cities organizing group and brought it into Riverside and propose that we do it. We went off to the races with it because we had the support of our city. In Riverside, we've done a whole series of education programs that are videotaped and are available on our [city website](#).

**Health Hats:** I looked at that. That is impressive.

**Jill Johnson-Young:** I did Dementia 101. We had to do hospice - what to expect, caregiver support, all the things that people with dementia don't know that they need, especially the families. Because when you have dementia you don't know what's coming and you don't see what you need until you need it. We try to jump ahead of that, and then we looked at how do we make our community better? People got together and volunteered to identify banks that were more aware of fraud and restaurants that make it impossible for people to go out. Going out to eat is just such a normal family thing. And you can't do it in a typical restaurant with dementia.

**Health Hats:** Once the community energy coalesced to start developing this program, how did you bring in shopkeepers, the medical community, and day-to-day people? How did that evolve?

**Jill Johnson-Young:** Our Mayor has a right-hand person, named Cheryl, who is involved in everything. She got on board with this and put it out to her people. I'm a social worker, so I know people in a variety of places. We reached out to the home health agencies because they are the ones who were actually in touch with folks who were struggling to take care of someone. Our Office on Aging got involved and has been active in doing this. We have two Alzheimer's Associations. They're both involved. We have a lot of skilled nursing and adult living facilities who got involved because they are dealing with the families. It was a natural. All the people who do this are in touch with each other all the time anyway.

## Maintaining a Dementia-Friendly City 12:25

**Health Hats:** It's one thing to start something. It's another thing to maintain it. People who start are usually not maintainers. They have that new thing energy. Is there a coalition that meets regularly with some kind of governance? How does the community keep it going?

**Jill Johnson-Young:** The Mayor's office housed us. We had a monthly meeting set on a specific day, so everyone knew what it was. We had someone who took notes and an intern who put together the agenda that was sent out ahead. Then I would send in those of us who had activities going that month, and they'd go out as a mass email. It kept us connected. People filtered in and out. Rusty, the Mayor, went off to the side. He put together a *Night of Hope and Joy*, every other or every month gathering where someone serves you a meal. You can bring your person with dementia. You can hang out as a caregiver and not have anyone talking at you, lecturing you, or educating you. You just get to hang out, knowing that your person has got other people hanging out with them. And the food is dementia-friendly food. Because there is such a thing, and it's in a safe environment at the senior center. So, that was where he took his gifts and talents. A couple of volunteers recently took it over. When they get tired, they say, 'Hands up. I need help.' And folks just filter in. Now with a new mayor coming in, we're shifting over to housing at another office, but people are sticking with it, and we support things like the Alzheimer's Walk. I think because dementia is ongoing, all of us are still always going to be in it. Maintaining Dementia-Friendly City is one place where we can help each other out.

## Dementia-Friendly America 14:27

**Health Hats:** I looked up Dementia-Friendly Cities and saw the [Dementia-Friendly America](#) network. It looks like there are around 40 States represented on that website. How does this national organization support this? How does the community contribute to the national organization?

**Jill Johnson-Young:** It's a loose coalition. When you sign on, they send you materials, and you can choose how you want to do it. There is no 'You have to do this, and you have to do that,' which tends to scare people off. It gave us the freedom to figure out how we wanted to do it. For instance, we've now got the restaurant program going. We wrote the program. We've got it moving. We're moving on now to educating our first responders to know how to deal with families with dementia. We list ourselves with them. When people are looking for dementia resources, and they find them, then they can find Riverside on there and refer back to us. It's an extensive resource network.

**Health Hats:** That's great. In my career, the most successful public health innovations have come because people are trying to solve a problem in their community. There's always a local flavor, but people have been through it before. What you can learn, especially when you have a question as opposed to somebody saying, 'you need to know this.' We're trying to solve this problem. Has anybody else? It's sort of the same for peer support groups, whether they're on Facebook or wherever they are. I find it more valuable when I have a question, and I'm seeking an answer. I don't have that much tolerance. So, I have MS, and I go on the MS communities, and I'm not that interested in somebody saying, 'you should do this diet or take these medicines' or whatever. That's not helpful, but if I have a problem or I'm trying to solve an issue that I have, then you put it out, and people just come out of the woodwork in terms of being helpful.

When dementia comes knocking 17:07

**Health Hats:** What kind of suggestions do you give to families who are realizing that dementia might be happening?

**Jill Johnson-Young:** I have run a dementia support group for seven, eight years now. I started it because I saw a problem and I'm a social worker and we just sometimes don't quit. So, I started a community-based group. It's not affiliated with any of the associations because I frankly refuse to make it so because they had their own rules. I wanted to say it's for all the dementias.

**Health Hats:** It's not about just Alzheimer's or Lewy Body?

**Jill Johnson-Young:** Everybody come on. In that group, people come for the first time, or they come into my office the first time because they recognize that something wrong. We'll welcome them in and say, 'okay, now wait, wait, wait. Are you having this happening, this happening, this happening? You can see this look of horror on the person's face. It's usually the caregiver who comes, and they realize someone's telling them what they are going to be going through. These are people who've already been there. And then they can start talking about what they're experiencing because these are folks who can hold that and say, 'okay, yeah, we had that. Do you need help with that part?'

**Health Hats:** You said that these are people that can hold that. What do you mean by that?

**Jill Johnson-Young:** They sit and just listen, and they don't jump in and start saying, 'Oh, poor you' or make all the clucking noises. People do that. Sometimes you just want someone to be quiet and listen.

**Health Hats:** Yes. Quiet. Hold the space, the ability to absorb, right?

**Jill Johnson-Young:** Be the sponge. Then when they finish talking, when you know that they've said all they need to say, you can say, 'are you looking for resources. Do you just want us to tell you how we handled it? What? What can we do?' Then they will jump in with the helpful things. Like if you're already having difficulty with showering, someone's got the best technique for that. Because someone with dementia is already having experience with losing vision, they're not able to focus. They may not be able to see where the water's coming from in the shower. They may not be comfortable in a small room, and they may not recognize you at that moment. Suddenly, this person is trying to make them naked and put them in a box that has water falling out of it. Who wants that? So instead you help them go in; you leave the door open; you turn on the water, and you put them in with their clothes on. Nobody wants to be in wet clothes, and they will eventually take them off. Why fight?

We use the word fibblet. If you can't tell someone that their parents died 20 years ago, you say your mom went out to the grocery store, should be back to see you. It's kinder. I listen when someone comes for the first time to my office, and they're saying, 'something is happening, and I'm not sure what it is.' This has happened twice in the last week in my office. I let them tell me all the things, and I poke around, 'tell me what it's like when you're at home, tell me what driving is like.' And then I'll say, 'Tell me about your family history and your medical history. Have you been to the doctor recently?'

Find the right doctor 20:47

Unfortunately, doctors will frequently send people they suspect as having dementia to a therapist, and not tell them that they have dementia and say to the therapist, 'Could you assess them for depression, please, anxiety?'

**Health Hats:** Oh, my goodness.

**Jill Johnson-Young:** The symptoms are somewhat the same, but if 50% of doctors in this country won't tell someone they have dementia, ever, and they won't tell the family. It falls in the lap of the therapist to say, 'Let me read you some diagnostics for depression, and let me just read you another one and you tell me which one fits better?' There's a sense of relief when that person who's suspecting dementia hears you say, 'This is what I'm hearing. I'm not a neurologist. I can't tell you for absolute certain, but I want you to get to this particular neurologist, and I want you to get some tests done. And then we'll go from there and figure out where we need to be.'

**Health Hats:** This particular neurologist? As I told you, I have MS, and I go to a neurologist that specializes in degenerative diseases. So, there are neurologists that specialize in dementia?

**Jill Johnson-Young:** There are not very many. There are a lot of neurologists who specialize in everything. I do headaches, and I do this, and I do that. You don't want that person for dementia. You need someone who knows dementia. So, I typically will say teaching hospital.-Fortunately, I'm in Southern California. We've got Loma Linda, UC Irvine, UCLA. We've got all the hospitals—some areas not so much. And neurologists are few and far between in a lot of areas. But you have to have someone who knows dementia. Then you have to be forward with them and say, 'This is what I'm suspecting, and these are all the symptoms. This is why.' Because otherwise, they won't say it.

**Health Hats:** Are there parts of your community where primary care physicians are particularly experienced with dementia versus not?

**Jill Johnson-Young:** Yeah, we have gerontologists and geriatricians. And we have a couple of primaries that I trust. Okay. Because I've worked with them for a long time. If I send someone to them and say, this is what I'm looking for, then they will look there too. But we have a massive barrier with physicians in general. I don't know if it's true with MS, but with dementia, they feel so powerless, and there's not a lot they can do. We have some memory meds, but they only work for part of the population and only for a specific time. So, they just won't say it. They will not say dementia unless they have to pull a license, they're not going to say it. With my mom right now, we were just at the neurologist. I wrote a three-page note; these are all the symptoms I'm seeing. I need you to look at this because this is what I'm suspecting.' And he sat with her, and he went through the mini-mental status exam, which by the way, most people with dementia can fake for several years. He looked at her, and he said, 'I think we're having some issues. I want to get some psych testing. I want to get you to another physician.' Even he wouldn't say the word dementia. And he knew exactly what it was because then he told her she couldn't drive. He knew what it was. And he's an outstanding physician. It's a hard bunch to get through.

**Health Hats:** But that's a different kind of stigma, isn't it? There's the stigma of going to the restaurant or the grocery store, and people look weird at you. But it's another kind of stigma not be not being able to talk about it.

**Jill Johnson-Young:** Right.

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The 3C's and 2T's: trust time, talk, control and connection 25:40

**Health Hats:** I consider myself a patient, caregiver activist. Over the years, I've tried to think about pithy, short descriptions of different ideas or different concepts. One that I'm working on over the last few months, is something that I'm calling the *three T's and the two C's*: trust time, talk, control, and connection.

**Jill Johnson-Young:** I love that.

**Health Hats:** You've mentioned all of those.

**Jill Johnson-Young:** Yup. They are the most prevalent needs. How do you deal with an illness unless you can trust your providers and be heard and get the information that you need? That's why Dementia-Friendly Cities is so essential because it gives people resources cause they can go on our website. And it gives them also some dignity because if you're in a restaurant and you're confronted with a menu that's like the cheesecake factory, it's what, 45 pages or something long? Instead, someone can say, 'There are ten items here. Would you like one of these?' It gives you a sense of I'm still a person.

A dementia rich life 27:10

**Health Hats:** You've had experience with dementia in many phases of your life. Do you care to share a little bit about that?

**Jill Johnson-Young:** I worked for hospice for well over a decade in two States, and dementia is a hospice diagnosis, but people don't get to hospice soon enough with dementia. Those families that I'd run into had very little support and had not had a lot of people to talk to about it. The internet has sure changed that a lot because I can refer people to go to this group or that group, especially the secret Facebook groups where they can get on and talk about all the stuff they're hearing from people who were not helpful. As you said, say, 'This is my problem. Help me.' With dementia, this is especially important because dementia folks don't sleep at night—they sundown. So, when their caregiver is up at two in the morning trying to cope, they can hop online and talk to someone in England where it's 10 a.m. At least they can bitch about it a little bit. 'Tell me how I'm going to keep my sanity tonight.'

The short story is my first wife had pulmonary fibrosis. Both my first two wives were nurses, by the way. When she was dying, she became very close to her hospice nurse, Casper. They got along very well. She told Casper and the whole planet that she wanted Casper to come back for the kids and me. We told her to shut up. This was not Fantasy Island because it felt really weird. The focus was, you're dying of

pulmonary fibrosis right now. Ultimately, that did work out well. We got married, and then six months later, Casper started having all these weird symptoms that made no sense. We're on a Lanai in Hawaii, and her coffee cup flew out of her hand about three feet. Then she was not in touch with reality on and off throughout the day. Then she started shaking, and it took three years to get the diagnosis. She died six months after diagnosis. I was the one who finally had to say, 'This is what I think it is. Someone tell me that I'm not crazy.' So, I lived with Lewy Body in my house, and I lived through a Lewy Body death, which is pretty atrocious. Then I had my dementia support group that I've been running throughout that time. Now in my practice, I started focusing on that. I started with kids and adoptions and that kind of thing because that was my other part of life. But I found the need for people who were dealing with chronic and terminal illnesses - in particular dementia. Then grief and loss and death and dying. And as weird as that sounds, it's what I love to do.

#### A sense of humor 30:06

And I do it with a sense of humor. I was teaching a group in LA on the weekend, and the presenter across the way, it was a big convention, said, you know, we were crying in my room, and you guys were laughing. I said, 'Well, I'm sorry you were crying. But yes, we were laughing because we were talking about stuff that required humor.'

**Health Hats:** I'll tell you a quick story. My mom had pancreatic cancer, and she decided, 'I'm old. I've had a good life. I don't want any treatment. Then she decided that things weren't going quick enough, so she decided to stop eating and drinking. I live in Boston. She lived in San Diego. I would go every six weeks for five days. Anyway, one morning I got this call from her. She said, 'Oh, this dying shit is so boring.' Then a week later, she calls and says, 'I think it's the four P's: pillow, pills, poop, and piss.' I just appreciate that she had a sense of humor. Obviously, it wasn't all funny, not by a long shot. You need that humor. Close to when she died, she realized there was a fifth P: phone. She thought she was so clever that it wasn't P, you know, that it was phone. That's how she stayed in touch with people through her phone.

#### Self-care. Accepting help. 32:09

**Health Hats:** How did you take care of yourself? You were talking about this nighttime, not being able to sleep and being so thoroughly exhausted.

**Jill Johnson-Young:** Sundown Hell. When you have dementia in your family, you have got to have a village. Otherwise, you can't do it. That goes for all diseases, but with dementia in particular, because folks can be up and going, and they get agitated in a way that other conditions don't cause agitation. Lewy Body can be dangerous. There's a rapid eye movement sleep disorder that is now classified as homicidal in the ICD codes because it is so violent at times. I was able to have my brother-in-law, who lived in North Carolina, fly out and live with us, which meant I had to double down on work hours. But it also meant I had someone that my wife trusted and knew and whose voice she knew in the house with her at all times. My kids were adults at that time, and there was one still at home, and they were very close. So, she hung out with her a lot. I had hospice friends who worked for hospice, but they would come by evenings, weekends, days off. I didn't have some of the same crews that I had for my first wife's death, because when you remarry after you've been widowed, you're breaking the widow rules. Then people get all kinds of pissed off and stop supporting you at least for a while. But I did have some

others, and then I had the funeral director who helped me make arrangements with my first wife. She came and got her the day she died. She'd been watching me on Facebook, and she came in and started helping out in the evenings and on weekends. So, between a small group of girlfriends, neighbors, kids, when I needed to rest, I could take a nap. I would work all day for hospice, and I'd pull over on the side of the road and sleep for an hour and set my alarm and call one of my nurses on my team because I was the social worker for three nurses. They were my nurses, and I would call them and say, 'I'm tired, Jenny, will you wake me up in an hour?' And Jenny would call me in an hour, and I could get back on the road. There were days where I took Casper in the car with me because my brother-in-law wanted out of the house, but she couldn't be out of the house by herself. So, she'd ride along and then sit and wait under a tree while I saw clients

**Health Hats:** We had a son who passed away at 26 of metastatic melanoma. And one of the things that we learned in that last year is that people were very much wanted to be helpful, but they had no idea how to be helpful. So, we made it part of our routine every week. We had a family meeting every week on the phone - what's going on? What's coming up? Who's gonna do what? But part of it ended up thinking about what can we ask people to do when they are offering? There are only so many casseroles you can eat.

**Jill Johnson-Young:** Can you do the laundry?

**Health Hats:** Right. We need this shopping. Coming up with three things this week that we need that somebody else can do? There were times where we asked people for help, but I think mostly there were just people there wanting to help.

**Jill Johnson-Young:** What happens in dementia is people don't know what to do. The caregivers are reticent. It's hard to explain what's going on and how to do the care. So, when my first wife was dying, I started writing a blog. Then when Casper began to get sick, I went back to it. It was my way of communicating what was going on without having to reach out over and over and over to people. You just don't have that energy. You know that from your son and promotion of your illness. And so it was, this is what's going on. And there was humor involved. But then I also occasionally would write like an instructional one. If someone is sick, these are the things you never say to them. To your hospital, I know that you thought that I was just a caregiver, but I'm a wife too, and you need to talk to people in this manner. This is what people who are taking care of someone need at home, and they're not going to ask you for. So, if you know someone, look at this list, call them and say, may I do this piece? And they will be surprised. And because you're offering that specific, they'll say yes. And that's kind of what I did. It was, yeah, I need help. And then when I, when it was a dreadful night, - and I started talking about it, someone would just show up on the doorstep saying, I saw what came up. I'm, I'm over here, put me to work. That's great. Yeah. I'm very fortunate.

**Health Hats:** This has been great. Thanks for taking the time. I really appreciate it.

**Jill Johnson-Young:** You're welcome. You do a good service.

Reflections 37:54

Often – most often? - innovation comes from people trying to solve a problem near and dear to them. They start with a germ, build something alone or with others, and scale it to their community. They test,

they adapt, they share. Sometimes similar innovation happens elsewhere and those people loosely affiliate. If money is to be made, it gets bought. Most really good community innovations are not money makers. They're value makers. So Rusty Baily, Rich Gradner, Cheryl, Jill Johnson-Young and other nameless folk needed something better for their family members with dementia and created the Purple City Dementia-Friendly City. The bonus: it sustains without them. Trust, connection, and control. Pretty damn cool! Thank you Tania Marien for introducing me. I've learned a lot. Please see the references and links in the show notes. Next week I'll share my interview with Stephanie Oden, Executive Director of the Gardens of Riverside Memory Care in Riverside, CA, and Jennifer Keeney, flutist and daughter of Jerry Keeney living in Golden Pond Memory Care in Colorado. We'll talk about life in a Memory Care residence during Coronavirus days.