

Daughterhood The Podcast Episode #32: When Your Aging Parent Needs Help with Dr Leslie Kernisan

RESOURCES

Book - When You're Aging Parent Needs Help: A Geriatrician's Step-By-Step Guide to Memory Loss, Resistance, Safety Worries & More

<https://www.amazon.com/Aging-Parent-Needs-Step-Step/dp/173615320X>

Free Online Course – Memory Loss & Safety: How to Have Better Talks and Fewer Fights With Your Aging Parent

<https://betterhealthwhileaging.net/education-and-support/>

<https://betterhealthwhileaging.net/>

SUMMARY KEYWORDS

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SPEAKERS

Rosanne, Dr Leslie Kernisan, Disclaimer

Disclaimer 00:02

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Rosanne 00:42

Hello, and welcome to Daughterhood The Podcast. I am your host Rosanne Corcoran Daughterhood circle leader and primary caregiver. Daughterhood is the creation of Anne Tumlinson who has worked on the front lines in the healthcare field for many years and has seen the multitude of challenges caregivers face. Our mission is to support and build confidence in women who are managing their parents care. Daughterhood is what happens when we put our lives on hold to take care of our parents.

We recognize this care is too much for one person to handle alone. We want to help you see your efforts are not only good enough, they are actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system. Provide resources for you as a caregiver as well as for you as a person and help you know that you don't have to endure this on your own. Join me in daughter hood. Dr. Leslie Kernisan, MD MPH is board certified in internal medicine and geriatrics and has been practicing geriatrics since 2006. She created her website better health while aging.net in 2008. To provide practical, actionable information for older adults and family caregivers grounded in what geriatricians believed to be optimal health care for older adults, Dr. Kernisan's book *When Your Aging Parent Needs Help a Geriatricians Step By Step Guide to Memory Loss Resistance, Safety Worries and More* is the ultimate guide in respectfully engaging your parent with a practical plan to get help for the most common worries, including safety concerns and memory loss while respecting your parents dignity and autonomy. I hope you enjoy our conversation. Your book was I was reading it I was I was kept thinking, oh my God, like oh my God, you have scripts you have if this happens, try that. If that happens, we'll then try this. It's it's a guide. And you know, there is no guide. In this world. There's no map, there's no guide. But that's what your book is. What made you decide to write this book?

Dr Leslie Kernisan 02:45

Well, I wanted to write this book because there were a couple of things that went into it. One is that we were getting questions often about this type of situation on better health, while aging where people had noticed worrisome changes in an aging parent that maybe sounded memory related, maybe not, and had tried to talk to their parent and get their parents to change things. And the parent had refused, and they were stuck. So this kept coming up. And I thought about it. And I have been for the past several years, just envisioning this as a journey people end up on, they end up on his journey of helping an aging parents. And there are different ways the journey starts. Sometimes it's with a sudden health crisis, some older parents are actually inviting their kids to start helping or asking for help earlier. But for some people, it really starts with this nagging feeling of worry and being unsure of what to do. And so I wanted to provide people with a resource for that, because I felt like that stage is quite tricky to navigate. And when I looked at what was out there for caregivers, it often presumed that people were already in the caregiving role, like here's how to care for your parent who has Alzheimer's or dementia, or here's how to be a good family caregiver. And I thought, Well, what about this early stage where you realize that you might have to take on this role, and you're not sure how to step into it, your parent is often not expecting or opens you. Nothing into it, especially if there are any memory loss problems. How do people get through that? And I mean, with many things, aging parents, millions of people go through this every day, right? Most of us are fortunate to have our parents live long enough that we see them age and kind of change. And yet over and over again, people find themselves kind of looking around feeling like what the heck now lads, and are kind of unsure where to turn to so so one is I felt like there was a real gap there. And the other is that for years people, you know, have asked me questions like, How do I know you know, should my mom still be living alone or there's this or that? What should I do? And I sort of thought about what I do as a geriatrician and? And I thought about, well, how can I turn that into something that could be a roadmap for others? Because part of what I do as a geriatrician is step back and say, Well, let me look for specific signs that there's a problem with memory and thinking, or was how they're managing their life. Let me see how they feel about it. Let me then make a plan to step in. And I thought, well, you know, I could create a version of this for for family members, I also realized that we have certain ways that we explore these issues with older adults, and

that we could maybe teach some of those to family members as well. And so that was basically the genesis of the book, it's been a little tricky sharing it, because it doesn't, I think, fall neatly into categories, because a lot of things about caring for aging parents are our memoirs, you know, or sometimes encyclopedic, you know, for this problem, do this for that phone, do that. And then I was like, Well, sure. But that's, that's assuming you're already there. In the role, how do you get into the role. And so that's what led me to do the book was my co author, Paula Spencer, Scott. And she has actually written a lot about family caregiving and aging parents. And she also said, you know, I don't think I've ever seen anything quite like this. And so we thought, it's going to be an expanded version of what I do on better health while aging, which is to kind of break things down and try to provide people with something that's really practical, and it can enable them to take better next steps for their own health or their family's health. And so that's where the book came from.

Rosanne 06:34

Well, and thank thank you for writing it. Because, honestly, to have an actual geriatrician, write a book like this is so helpful, because you are providing that and you know, for the general public, you don't get this from from a doctor, you don't get this.

Dr Leslie Kernisan 06:52

Right. Well, that's definitely what's the genesis of better health while aging, in general, is that I realized that people often have questions and problems that we have the training and experience to provide guidance on, but most people will not be able to talk to a geriatrician, there are not very many of us. And at the time, when I became interested in doing this online, which was in 2008, the Internet was taking off as a resource where people would Google their questions, but I was actually invited to answer questions for a website called caring.com. For boomers read about aging parents, and when when I looked, I thought, well, this health information is very mundane kind of disease, you know, one disease at a time, you know, for people who are middle age, this is not what I would tell older adults or family members, but I thought what an opportunity, people are going to Google asking questions where we know a lot about what they could or should do. And so what if we were creating materials that they would find because as you know, the most important member of the healthcare team is supposed to be the patient and their family members, right? And so what if we could teach a geriatric approach to families and older adults online. And so that really shifted my career, I decided that this was like, but I loved to do teach online in this way. And eventually, I created my own site. So but the book was really finding something that I felt was a persisting need, and was more than I could address in an article. But a book with the sort of series of steps seemed like the, you know, a viable solution. And so that led to the book.

Rosanne 08:36

Absolutely. And, you know, you have checklists in there. And then you have, okay, so you go through the checklists, and then actual words, actual, this is how you say, these things. This is how you say I'm concerned without wagging a finger without saying you can't do this anymore, mom, without any of that. They are legitimate conversation starters. And actually, the script is there for you. There's so many things that go along with this because you don't want to, you don't want to believe that what's happening is happening. What you were seeing is actually what you're seeing. And then you go to the

doctor and the doctor goes in, it's fine. And then you think, okay, great. All right. Well, nevermind. But you know, it's not nevermind, you know, there really is a problem.

Dr Leslie Kernisan 09:21

Yeah, and we definitely wanted to give, I definitely wanted to give people the tools to get around the fact that doctors often say, it's fine, fine. A lot of Yes, was from because by the time I wrote the book, I'd already been running better health while aging for several years, where we were getting, you know, questions every day, every week from people and I'd also been running these online, helping older parents programs. So I started that in 2018. I start off with a boot camp, and we expanded that and so you know, I see where families are stuck because they asked me and I also see what is happening when they go to other doctors and I've also, you know, been in primary care. And it's an issue in general in health care quality that often doctors for various reasons are not providing, especially older adults with the ideal care. And that's partly because they haven't had the training and because the system isn't set up. And so I wanted to give people the tools to understand what to expect and how to work around it, and how to be a better advocate. So, so what a lot of other experts told me is, well, you can't tell families what to do, because every situation is different. And I thought, Well, it's true. It's not possible to give people a list of do this than that than that than that than that. No, but I felt like well, I can show you how to work your way through and figure out what might make sense for your family. And there's a common starting point, I would say, which is, and so in the book, we organized it into four sections, the first taking stock, the second taking aim, the third taking action, and then the fourth, taking the long view. But I felt like well, the the taking stock part is things that are a good starting point for anybody who's concerned. Exactly. And then, in taking aim, we chose to focus on the, you know, the ideal way that common problems in older adults who have this is really geared towards people who have an aging parent who's been independent, and seems to be shifting out of that, I would say the book is not great for people who've had a parent in, you know, a nursing home for years are with like, I mean, we've had people read the book and give us the feedback that there were still helpful things, but I think of it as really for that person who's had this relationship with their adult parents who's getting a little older, but you know, just slowing down a bit. And then they start to get this feeling like, wait, what's what's happening happening? Are you doing that? Or are you okay? Or shouldn't you change things? I really wanted to create something for them.

Rosanne 11:57

Well, it took me through that. What does that look like, you know, you, you start to see your father not socializing, you start to see him sleeping more, you start to see things around the house that weren't around the house, what are the things that somebody should be looking for in that change, that they're nuanced? Sometimes they don't hit you over the head, sometimes it's not this big thing that happens, sometimes there's nuances that are changing, that you may not notice, or you or you kind of do, but what what is it that you should be looking for?

Dr Leslie Kernisan 12:26

Yeah, so um, so the first part that we recommend is taking stock. So I start off by telling people that you know, the instinct is really to kind of jump in telling your parent, listen, you need to talk to the doctor, you need to do this, you need to think about moving the house is too big, you know, and let's change our entire life. And I don't know why you're mad at me, exactly. For suggesting that. Yeah. So we tell

people to start off by taking a step back. And that, you know, what we recommend, what I recommend is that they do a kind of more systematic process of taking stock, and people are often not sure what to look for. And they're not sure what's normal and not normal, and what's worrisome. So hence, we create the cheat sheets. And, and we talk about taking stock and kind of two parts. One part is you're going to directly like, try to observe or check for signs that are concerning. And the other is before you keep telling your parent what to do and what you think and your concerns, you're actually going to spend some time trying to better understand the third perspective, how they see it, what their concerns are, what's most important that you're there to listen, so on the sign of what to look for. So as a geriatrician, whenever I hear that an older adult is either having difficulties or resisting things that other quote, reasonable people think they should do, one of the first things that comes to my mind is, are we dealing with a memory or thinking issue here, because not every older person who's declining or wearing their family is having memory or thinking problems. And especially as people get older, into their 80s and 90s, it's actually fairly common. And even if they're younger, it's really important to determine whether that is happening, because it will, it should change the way we talk to the person. And, you know, I was, as I was thinking about, like the branching points and how you decide how to move forward, people, if they are in their right mind have the right to live their lives in ways that I as a doctor would say, is not the best thing for your health that might worry their children that other people might not approve of. I mean, unless they're creating a real community health hazard. People have the right to take risks with their life and house but that's assuming they're in their right mind. Right. So I felt like well, this is this is a very important thing to determine because if we think they are slipping mentally, then it becomes ethically and eventually legally more permissible to step in a little bit more. So we do have a whole you know, series on checking for signs of memory and thinking problems. To help people understand what is not normal, because I had so many people tell me that short term memory loss, you know, frame it as normal, you know, when they tell me their parent is having difficulty, while like, any concerns about their memory and thinking, Oh, no, I mean, you know, their memory short term memory shot, just like you know, but that's normal at her age. And I'm like, That is not normal right now, if they're no longer able to cook a meal the way they could, that is not normal. So, so yeah, so we do have these lists, and one of them is for cognitive symptoms. And another one is for helping the person assess like daily life tasks, what does their parent seem to need help with or have difficulty doing? And we do that in geriatrics, one, it can be related to problems with memory or thinking or sometimes it's just physical limitations, maybe they just need adaptations made to what's going on with them physically. But also that points the way to how could we provide some additional support to help them maintain their independence and their well being. So those are the the checklists we have. And what we did in the book is in kind of a, I forget the exact size, it's like six by nine or something like that. It's not a normal paper size. But we wanted people to be able to use the cheat sheets more easily. So we actually offer them as downloadables from the website. So if people bought the book, they can come to a page on better health while aging and enter their email, and then get them as PDFs that we can use, if that's a little easier. Yeah, so that was the first step. So on one hand, we have, you know, here's what the check for. And initially, just observe or talk to other people know, your parents, it's good to be somewhat discreet, just, you know, you don't want to put you on the defensive. And then on the other side is having the conversations. And so there are two, we sort of broke it down into tips and suggested phrases all based on where we've seen families stumble. And it's normal for people to stumble. Because this is not obvious. I mean, even though so many of us will go through this, most of us do not

get taught or training or access to it until you're just there trying to figure it out as you go along. So I was trying to create that resource for people,

Rosanne 17:18

Well, and then you're in a panic, and then you're in a panic, like, Okay, what do I do, and then good decisions don't come out of panic. And it's, it's hard to then take it all in and try to try to think about it objectively. But the key Also, throughout it all is to have a little is to have compassion for whoever it is, you're trying to help. Because they know things are changing. And it's it's sometimes terrifying to think that okay, then all of this is going to go away, and it's going to be different.

Dr Leslie Kernisan 17:49

Yeah, we also try to emphasize, like the adult child having compassion for themselves. Because I think, you know, another sort of recurring theme I have seen over the years is people taking on a lot of pressure to feel like they need to fix this and make it just right for their parents relatively quickly. Yeah. And the truth is, that's not probably your job as the adult child to fix it all and get them the right outcome. We sort of tell people that your your job is to show up, and learn to speak to your parent more constructively, and learn to research and help point them towards things that could be helpful. Yeah. And you know, to take steps, but you have to let go of this idea that you're only doing a good job if you get them the perfect living situation, the perfect safety situation, that I understand why we want that for our parents, we love them, we we want them to be safe and know that they're well cared for and that they're doing the things that are good for their health. And we want them to be with us as long as possible. And I find that as people start letting go with that, trying to get that perfect outcome and instead thinking about how can I take a good next step right now that seems to help?

Rosanne 19:02

That's great advice, because it's true, especially when it comes to cognitive issues. And dementia. Specifically, you're not going to win this fight. There is no winning, but part of the trying to make it better and trying to fix it, which you can't fix. It's an unfixable situation, but that is part of your caring. And when you are in those positions, it almost becomes here. It's your responsibility. Well, you're not just going to take it and throw it aside. You're going to try to do it to your best of the best of your ability. Right. And part of that is trying to make it better. Yeah, so it all gets twisted in there, but you're fighting a losing battle. But it's like you don't realize you're fighting a losing battle because you've got to make it I've got to make this better. If I can do this. It will be better. If I can do that. It will be better, right? So that advice is it's it's a, it's a cold water in the face. Yeah, cuz you're right, you're right, you just have to do the next decision that you can make for their betterment.

Dr Leslie Kernisan 20:13

Right? And yeah, it's interesting with Alzheimer's and other forms of dementia, I mean, so first on the book, we sort of emphasize that even if a parent seems to be having some memory and thinking problems, we don't want to assume it's Alzheimer's or dementia right away. Because sometimes there are other medical conditions that could be treated, or I will say, you know, most of the time, there is some kind of underlying chronic brain change that is going to slowly get worse. And there are often many things we can do to help the brain think better and be the best it can be in that moment. And so again, we're reframing what is a win, you know, a win is, you're not going to get the win of getting them

to be the way they were 10 years before, right, and getting things to a point where their brain is going to stop changing, and they're going to stop getting worse. But what we can do is often find ways to help them live better in the world, or to have more time connecting with them, which is really important to them, even if you're not fixing things. Right, a Geriatric Care Manager, I know who helps people with difficult, you know, older parents once said that, you know, sometimes what adult children needs to do is accept their parents complaining and dissatisfaction. So sometimes, if they're complaining about things, if we just fix it, they'll stop. But there are a lot of parents who have been complainers, their whole life, people in general who've been complainers their whole life. And weirdly, once you realize that you can support them by being there to listen and not right away trying to fix it, or try to get them to see the bright side, you know that just that. And I think of it as like walking with them on that journey, just accompanying them on it, even if it's going to a place that often neither of you really want to go to, which is more changes, changing abilities, changing roles, you know, you can accompany them on that. And your companionship is the win, not that you got them to a significantly different destination, because in the end, we all kind of end up at the same destination.

Rosanne 22:24

Right. Agreed. Now, I often hear that. Well, it might not be dementia could be other things. What are the other things? What what could mimic that?

Dr Leslie Kernisan 22:32

Yeah, so we have a cheat sheet on that also, in the book 10, you know, common causes of memory and thinking changes and 10 things that doctors are supposed to check for. So initially, if an older person is showing signs of difficulty with their memory, or thinking or ability to do daily tasks, they should be, we want a medical evaluation to kind of figure out like, why. And that should check for common conditions that can make memory and thinking worse, and try to reverse them if possible. So they include things like medication side effects, abnormal levels of blood, sodium, or calcium will do it. Thyroid Problems can do it, vitamin B, 12 can do it. So there are more of them. But you know, we have them on that list. Sometimes it's delirium, which is the sort of becoming confused or, or confusion that's worse than usual. If the person was already confused, after an illness or a hospitalization, it could be that now people often want to know like, couldn't it be a urinary tract infection?

Rosanne 23:37

Because after very quickly, the great equalizer, yes,

Dr Leslie Kernisan 23:41

yes, urinary tract infections are common and can make older people confused, they do not generally cause them to be confused and have difficulty for weeks or months. Right. So if it's been going on and slowly getting worse for weeks or months, I would not attribute it to a urinary tract infection, I would be looking for other things. Now. You can check the person's urine and they might even grow bacteria. And they might also have a UTI at that moment. But what's more likely is that their bladder is just colonized with bacteria, because that's something that happens to people as they get older. It's called asymptomatic bacteria. And so sometimes older people are caught in this loop of being treated over and over, in hopes that it's going to fix the UTI and fix the memory and thinking and I think most the time, that's not very realistic. So yeah, but I'd speak to that since I know that's a common question.

Rosanne 24:34

No, that's fine. I remember, every time there was a change in my mother's cognition, I was like, oh, must be a UTI. And when we do the urine sample would come back and be like, nope, and I'd be like, now okay, well, I guess this is our new place now, but that's because that's all you hear. But thank you for clearing that up. Now when you do find that things are changing in And nobody wants to address it. Your parent doesn't want you involved. Your your siblings won't look at it. The friends are like, Oh, no, he still shows up and plays cards. What do you call that? watchful waiting? But what do you do in that area? I call it self caregiving myself, but watchful waiting, what do you do? In that? How do you try to support them, and then try to go back to bring that up? Like, maybe we should look at this?

Dr Leslie Kernisan 25:26

Yeah, um, so I guess we have watchful waiting, and the taking action part. And the method in the book is that first take stock take a really good look, you know, what's going on what your parent is having difficulty with how your parent feels about it. So Nexus take aim, which means you learn about, like, the ideal ways that whatever you observed, would be evaluated and managed. And so in that part of the book, I describe in depth how if there is a memory or thinking problem, how it would be evaluated, manage also how social workers or Geriatric Care Managers often arrange for additional support, you know, getting documents in order, and you know, the ideal things that would be done. So then in the last part, we tell, or in the third section, taking action, we help people, we actually have like a worksheet that they can go through to review what they've learned so far, and what they've learned about the options and pick a few that they think are feasible. And there we tell people something that I think is really important, which is that when you try to take action to help your parent, you should expect it to take a few tries, right? That it almost never works the first time that you have to try bringing it up or suggesting something. And we have a saying like no plan survives contact with reality, but you still have to make the plan. You see what happens, you say, I'm going to try again, later, I'm going to adjust a little thing, and that it often takes some persistence. And so then if after giving it several tries, you're still very stuck. That is when you step back and say, well, maybe I need to take a totally different approach. Or maybe I'm going to watchfully Wait, which is basically like you leave things as they are, people often feel extremely uncomfortable with that, like I'm doing nothing, but we tell people, you're not doing nothing, because ideally Watchful Waiting is after you've made good faith attempts to learn the better ways to do something, and you've made good faith attempts to try to get those implemented. Okay. And if you have done that, then now Watchful Waiting is because you've tried these things, you've determined that it's not really easily feasible, or it's creating distress for your parents. And now it makes sense to wait. But I feel like it feels more ethically permissible after one has made the attempts.

Rosanne 27:48

And you yourself have to almost become what you do, you have to learn about what you're seeing, you have to learn about what the potential could be. So during that part, it's almost like you're gathering information.

Dr Leslie Kernisan 28:02

Yeah, as you're as you're waiting as well. But I, I sort of tell people that there's, there's a difference between leaving your parent as they are, because you're not sure what to do versus having done, put

in the time to learn what could be done. And the book is there. To make that easy, you know, better health, while aging has information on what could be done, then to make a few good attempts. And then to sort of say, well, now I'm going to wait until they get worse or something happens, that's totally different. Yeah. And I tell people that if you have put in some time to learn more about how it could be done to learn more about how you could talk to them about it, and to make those attempts, then it's really reasonable than to end up at watchful waiting for a bit. And so one of the other things that we put in the book that that I really like about it that I think is also kind of unique about it is that we also created two families that the reader can follow to provide a really concrete example of what this looks like. So yes, we have the two families. And so in every chapter, we kind of explain what we think people should do and why and how, and then, you know, there's the story of the family and the adult child or, you know, in one family, it's an older mom and her daughter and the other family. It's an older father, and he has like three kids who are trying to coordinate together. But we sort of, you know, show people like what it looks like, as the adult children try to implement this part of it.

Rosanne 29:31

Yes, it's great because it's practical. Yeah, it's practical, and it highlights those issues. But it's, you know, when you're trying to make some headway, and there is no headway to be made. It's very frustrating time. Yes. Because it does make you say, well, then I don't know what else to do here. Like I don't know what else I'm supposed to be doing. Yeah. If nobody wants to, you know, identify all that is like okay, well What am I supposed to do?

Dr Leslie Kernisan 30:01

Right? Well, my hope is that the book for someone who's in that position will give them something where they can go through and say, Well, I did that I did that. I tried that I tried that, you know, look, I've gone through it. And oh, maybe now as watchful waiting, or maybe going through it, they'll be like, Oh, look, I actually didn't realize that there are experts called geriatric care managers, tons of experience with these kinds of situations, and maybe I could see if I can find one in my area to come help me talk to my dad. I mean, so many people who are in this position, do not realize that there are experts like that, who exist. So maybe your your audience is probably familiar with them. But geriatric care managers or, you know, they're not called aging life care professionals, they usually have a background in social work or therapy or gerontology. And then they've done kind of special training and learning to manage the the common challenges that come up for older adults who are facing challenges to their independence, you know, looking bringing in help in the home, but they also have experience with older adults who do not want help in the home and need convincing, right? Absolutely, yes, the local doctors and who might be good at helping to get an evaluation, you know, they, they are practical problem solvers. And they often have much more practical experience for what families are trying to do, than the doctors do. And how many of them are directly helping families and a hands on way. So So my hope is that the book can give people something to look through, to sort of reassure themselves that either they, they did try all the recommended things, or maybe to point out a few additional things that they didn't know about, that they could then look into,

Rosanne 31:39

I think, because the healthcare system is how the health healthcare system is, we have to look to other avenues, because you're not going to get that information from your doctor. Yeah. And it's, it becomes

one more layer of things that we need to do, instead of, I'm gonna go to the doctor, they're gonna give me a diagnosis, they're gonna give me all the information I need, and I'm gonna go on my way, that doesn't happen.

Dr Leslie Kernisan 32:06

No, definitely not. And definitely, when it comes to aging, what people need to navigate the challenges that come up are a combination of the right kind of health care and medical care. So figure out why are they having these changes, and you know, what can be done. And they also need adaptations and supports in their social and living situation. And so it cannot be done just by doctors. And ideally, it's something we would take on as a society is how do we adapt our society and our societal infrastructure to better support aging adults and their families? And, and not you know, is in the built environment it's in, you know, I mean, it's even in things like bank tellers, learning to recognize an older person who maybe is struggling with their finances, or, you know, yes, being exploited, it's in the fact that there's not a lot of affordable help for people in their homes, there's not a lot of affordable housing, that is a, you know, friendly to older adults or people, you know, with, with mobility limitations. And so ideally, we would be building that in to be a more Age Friendly society. And yes, when it comes to a lot of those adaptations, gerontologists are often, you know, have more expertise than geriatricians do, who are trained, you know, in medical care, but the the nature of our work is such that we know we have to work with people of other disciplines. And we know it takes a whole person approach to support aging adults, especially in the outpatient setting, right. And so we are often attuned to those other dimensions, I think a little bit more than other providers. It's one of our superpowers, we know other disciplines exist. Imagine that, you know, we can't necessarily work for them, but we know they exist and think we should get them involved. You know, whereas often medical doctors are pretty. Yep, doing their thing.

Rosanne 33:58

Yep. Well, but but, but then that adds another, it adds more time, it adds more cost, it adds more everything. And again, it shrinks that field to the people that can afford that in either time or money to go to an aging Life Care Manager. Well, they cost money.

Dr Leslie Kernisan 34:15

Yeah, they, I mean, they do cost money, because right now, as a society, we have not chosen to provide enough of this right for the population, which means people end up having to pay for it out of pocket. And I think it's a, you know, I think it's a crying shame. But there's, I think, a lot of worry that it would be very expensive to make these changes. I mean, I think to a certain extent that it it could potentially reduce expenses in that it could potentially help keep people from declining to the point that they need nursing homes or keep them out of the hospital. But often it's hard to make the health economics argument unless they're people who are already quite frail or what they call high utilizers. And what we want is for these kinds of supports and services to be available to our own parents and just regular people before you become the kind of high needs person that the healthcare system has identified as a high utilizer. And oh, well, now we're going to give you a case manager, right? Because will reduce your ER visits, and it's gonna save your insurance money. That's often how it works. Right now, which is, you know, which is that's a crime.

Rosanne 35:26

Yeah, it's a crime. It's, it's, it's just, I will never understand how we got here. And I don't know if it's going to change anytime soon. But that's where you it's one more burden on the caregiver to know what way to go, and which avenue to go down? And how to utilize it and navigate it. And Where's where's the road?

Dr Leslie Kernisan 35:58

And often pay for it.

Rosanne 35:59

And it's often pay for it. Yeah, yes, yes.

Dr Leslie Kernisan 36:04

Yeah. So no, I mean, I don't know, historically, there's been, you know, they say, in a way, it's kind of like structural ageism, absolutely, there's not a ton of, you know, there's not enough interest and energy into the needs of older people. And perhaps some of that is that many of us feel uncomfortable thinking of ourselves as the kind of older person who might need some support and assistance, we all want to be the person who gets to be 98, and is still driving their car, during their grocery shopping, mowing their lawn, and, you know, is like a slightly more bent and wrinkled version of who we were. Right? Yes, often held up as like successful ageing, and what everyone is shooting for. And I think a lot of people would prefer to plan their funeral than plan for what you know, they might do if they didn't have all the abilities that they have, you know, now, so there's, there's a lot of discomfort around it. So the book is really only like the starting point. Because after that, you know, the last part is, now you've have to start getting ready for as you know, what is often a longer journey, nobody knows exactly how long one's journey is going to be. But you know, often years of learning the next step in how to support your parents, and in, in how to help them out. So So I did create a follow up to the book, because I think the issues around memory loss and early dementia are so challenging. I did create a follow up course, that is helping older parents with early memory loss. So you know, for those people who find that their parent does have a memory loss issue, you know, sort of specifics on how to learn more about the kind of communication that works for parents with memory loss. And the most important things to do early on, when your parent is still semi independent, or often still quite independent, you know how to provide negotiate that support, and if needed supervision and preparing for later. But one of the reasons why I did it is because we actually know that if a person has a condition like Alzheimer's or dementia, one of the most effective interventions for improving their quality of life and well being is for the family to get a package of teaching and support on how to talk to them, how to manage common safety issues, how to support them, that actually makes a bigger difference, I think, than the medication EPS, which medications we have right now tend to not make a huge difference. But even though we have, you know, academics have developed dozens of effective programs to teach families this, they get a grant to develop the program, they develop it, they get a grant to study it, they study it prove they demonstrate it improves outcomes, then the grant funding runs out, the program disappears. Yes. And that drives a kind of, we're going to create our own, you know, I'm gonna create my own version of this. Yeah, because I know people need this help. But I also feel like, and unfortunately, people have to pay out of pocket for it. I think it's still, you know, reasonably priced. They actually, you know, people get to ask questions on live calls with me and our geriatric care managers. But I also feel like, Why do I have to do this this way? Yes. You know, why? Why doesn't everyone have access to this more easily, right.

But it's harder for me to fix access for everyone publicly than it is to create something myself and start offering it. So that is what I do for right now.

Rosanne 39:40

Because and thank God, and great and thank you, because there has to be help. And it's really easy to just think everybody's going to take care of everybody in their life, and we're going to go on and everything's going to be fine. There needs to be the support. There's no training there's no you You know, there are things 60% of caregivers do nursing duty at home. Nursing duty. Yeah. Listen, I was awful in math and science. That's why I was an English Communications major. You learn what you learn. Right? Right. You Learn it, because you have to learn it.

Dr Leslie Kernisan 40:14

Managing medications

Rosanne 40:16

Totally

Dr Leslie Kernisan 40:17

Monitoring all the health conditions.

Rosanne 40:19

Yes. Yes.

Dr Leslie Kernisan 40:20

Dealing with the finances. Yeah, researching options for paying for care. I mean, the it's really quite big.

Rosanne 40:28

Yeah, it never ends.

Dr Leslie Kernisan 40:30

What people go through

Rosanne 40:30

Yeah, no

Dr Leslie Kernisan 40:31

And it kind of keeps going for a while.

Rosanne 40:33

It does. And it's and it's just, it's just the one more thing that you have to do. And what are you going to do not do it? Of course, you're going to do it? Yeah. Yeah. Yeah. But then, here you are. And it's, it's that constant churn?

Dr Leslie Kernisan 40:46

Yeah. Yeah, no, definitely, I wrestle with that a little bit. Because I feel like while the book is helpful, the programs are helpful. And I know people are helped, and they still often just have, you know, a challenging time for a while. And so I think just as we tell people in the programs, that you have to give yourself some grace, that you're not able to change all the things you wanted to for your parents, right, you're walking alongside them doing what you can I sometimes tell myself, I have to give myself some grace. But I cannot fix this for every family the way I'd like to. And what I can do is try to accompany people and offer at least some help and support. But um, it's hard, I would really, like I would love to see things would be very different for aging adults and their families, you know, especially at that stage where people start to have their abilities change and need some additional support. So I mean, there are definitely challenges that come up in aging before then, you know, ageism is significant changes in role in identity. I mean, I don't want to minimize those. But I think there's a particular challenge time that a lot of people will go through where they'll feel their abilities changing, and they're gonna have to adapt to that and their families. And I feel like it's never going to be easy for people, but it's so much harder now than I think it should be. And that's a little bit heartbreaking.

Rosanne 42:06

Yes, yes. And if you could change something, if you could wave a magic wand to change the system, what would you do? How would you change it?

Dr Leslie Kernisan 42:16

Whoo. That's a good one. Wow. I mean, I feel like ideally, every older person whose site at some age related to clients would be able to be seen by a team, including a geriatrician and a good Geriatric Care Manager, who's not out of pocket paid to do a good evaluation and arrange for the right supports, there would be that we would have, like more, you know, affordable housing that supports people in this stage of life. Yeah, we'd have like better leave policies for you know, families, but I feel like families need leave for their short term crises. But that doesn't get them through the

Rosanne 43:05

The 12 year span of the years of caregiving

Dr Leslie Kernisan 43:09

The years of you know, helping, I mean, for that, I don't know that it should be all on a family member, that we should really have better societal systems to help provide some support and care to those older adults who need some of it. So that your role as a family member is again to accompany your parents kind of emotionally, you know, on the journey, and, you know, yes, you're going to end up like, having to arrange their affairs and help make better decisions. Not always, but in many cases, you know, if your parent loses the ability to do so I think it's appropriate for family to take that on, but all the other stuff they have to do. It's just a lot, especially given that it often goes on for years. And as you know, it'd be you know, it especially affects women, but affects men too. People cut back on their jobs, they lose earning power, it affects their health. Yeah.

Rosanne 44:07

It needs to be a complete overhaul. But we have to be able to look at the actual issues and not just say, well, they're old, it's like no, no, that doesn't play. No. Because that whole thing, it's, it's systemic. Well, I mean, ageism, it starts I mean, it just, yeah, it's infuriating. It's infuriating,

Dr Leslie Kernisan 44:35

But I think the subtext is also that it's expensive.

Rosanne 44:38

Yeah, well, everything is

Dr Leslie Kernisan 44:40

Yes. And, you know, politicians are afraid of getting on the hook for something expensive. voters don't necessarily like not being taxed for something that's expensive. And I think that's, you know, a significant obstacle is nobody's sure how to pay for it right? So

Rosanne 45:00

No, no, but nobody was sure how to pay for daycare programs and those types of things for young children. There's lots of things. And then once you get to 55, can't help you. Good luck. I mean, Medicare, when you get to 60, when you get on Medicare, they don't even pay for hearing aids they don't pay for hearing aids

Dr Leslie Kernisan 45:21

they pay for a lot, but not as much as people think they will. And they don't pay for long term care another thing people often don't learn until their in it.

Rosanne 45:31

And then they say, wait a minute, what? And it's like, no, they don't pay for long term care. There's no long term care, there's no caregiver options. There's no hearing aids, and the fastest way to dementia is hearing loss.

Dr Leslie Kernisan 45:42

Yeah, no, it's true. There's a lot of you know, a lot of the research suggests that helping people correct their hearing in mid life can delay dementia possibly prevented, but probably it's more going to be a delay thing, but that's super important.

Rosanne 46:00

Yeah. So you would think that they would cover something that would be helpful, but you know, neither here nor there. So to assist caregivers, what is your best advice for their well being, because what happens is you get on this, you get on this treadmill, and you're on it for years, you're on it, and you forget everything else about your own self and your own well being?

Dr Leslie Kernisan 46:23

Well, I guess what I often tell people is, first of all, don't stay alone, you know, find people to help support you. So they're, you know, especially nowadays, there lots of online groups of people helping

aging parents or other older relatives, find those, or potentially see what else is available locally or online, where you might also be able to tap into expertise from experts, often locally that groups run by social workers. And then you know, I offer some programs online for people as well. I would say, you know, kind of, do think about how to make this sustainable, you know, that this is probably something you're gonna have to pay attention to for a while. And ideally, like work at it steadily without letting it consume you so that you have energy for the crisis moments, which are going to come. So when you're between crises looking around, and sort of like how can I pace myself. And that might mean, not taking on too much for too long, that might be thinking about coming back to is there a way for me to get siblings to help a little bit more. As you know, in a lot of families, if there are multiple children, one of them ends up becoming the designated child, and then often the others are not doing as much and that person gets very burned out, in part because they didn't kind of slow down enough to, you know, work on getting help from others. And it's often not easy to get help from other siblings, but I think it can be a worthwhile investment, to put that time into seeing if that can be negotiated. So yeah, you know, just helping people think about, like, what's an approach I can take so that this is not going to totally chew me out, because your aging parent needs you. But there are often other other people and other things that need you as well, you know, there may have other family members, your spouse, your own children who need you, you may have a job, that means a lot to you, and that you mean a lot to the that position or that role. And I feel like I'm often encouraging people to find this balance, because their aging parent is so important to them, which I understand. And I also feel like often, you know, your parent wouldn't necessarily have wanted you to sacrifice everything for them, you know, they're just not able to tell you that it's okay to take a break, I look back a little bit and said, some of that, you know, and get support in renegotiating the commitments so that you can take care of yourself, because it's very easy for us to say, Oh, just take care of yourself. People are like how? And, and I think again, you need other people with you to support you and encourage you and, you know, grieve with you, when you grieve that you're not doing as much as you want it to.

Rosanne 49:08

Yes.

Dr Leslie Kernisan 49:09

You know, and coming to terms with that.

Rosanne 49:11

Yeah. And if you don't have those people in your life, find them. Find them because they're out there. If they're not if your siblings, aren't those people, if your friends aren't those people, there are people we're all out here. Yeah. Because you do you just need the support.

Dr Leslie Kernisan 49:27

Yeah. And and then for people who are earlier on if their parent is having memory loss, I find that people underestimate the value of learning better ways to talk with their parents. They think that they think that the doctors are gonna tell them what to do that like most doctors, even neurologists have very little training or experience and like coaching families for like dementia management, you know, the doctors are just like, oh, you could try this pill or maybe this test or maybe this fancy study and what you really need is to unlearn these better approaches to talking to them and managing the day by

day. And I find that people routinely underestimate that, and how much of a difference it can make. And I actually have a free training for people who are trying to get their aging parent with memory loss of be safer or stop resisting care. But, you know, one of the, like, things that I hear over and over again from families was a kind of light bulb moment for them was when we tell them like, you have to stop trying to explain Yes, to them, you can't win that. I mean, later, it's very obvious to people who've been in it for a while, but initially, like people just they keep trying to explain if I just say it the right way they'll understand and get us.

Rosanne 50:41

No, no, no.

Dr Leslie Kernisan 50:44

So you know, things like that.

Rosanne 50:47

Yeah, well, yeah. One, you have to accept those moments, you have to accept that things are changing. So you can't keep expecting things to be the same. When things are changing.

Dr Leslie Kernisan 50:56

Yes.

Rosanne 50:57

You know, you can see that they're changing, but you're still expecting things to be the same. And you can't.

Dr Leslie Kernisan 51:02

Right, right and I would tell people, you know, don't just try to figure it out by yourself. I'm a believer kind of in expertise in that whenever I'm faced with a problem, I look around, think there are people out there who know a lot about this and have figured out a good way to deal with it. And I just need to find them, or what they wrote, you know, I've noticed that other people have different temperaments, which is just like, well, if I keep just like trying to figure it out, I'll fall on it.

Rosanne 51:29

I'll get there. Eventually. I'm just banging my head on this wall.

Dr Leslie Kernisan 51:32

You know, I think that's kind of slow. So again, the taking aim thing? Yeah, lots of people have been through this. There are experts who've taken lots of people through this. So when you're stuck looking around, like who knows this really well. And I will tell you, it's usually not the neurologist, not the doctors, for most of this, you know, it's there are dementia care experts, geriatric care managers, there are social workers running dementia care groups. You know, I have my own program online helping older parents with early memory loss, you need to find a family members who have had a pair of taking care of you know, a spouse or a parent or someone with dementia can also become quite knowledgeable. I find that family caregivers have great advice on managing practical behavior

challenges. I don't always see them giving the advice that I would give when it comes to medications or certain health. Right. Thanks. So because I have sat in and watched these groups for years, you know, that's my own opinion. But if you're just like, how do I get them to take a shower? Right? Lots of families have grappled with that and figured out something. And it's also there's usually no exact answer. But you need to do is again, taking like, Here are several different things that people have found works, here's why. And then you decided you're gonna try your parents, and you have to trial and error until you figure out what works for your family.

Rosanne 52:56

A big thank you to Dr. Leslie Kernisan for being my guest today. For more information on Dr. K's book *When Your Aging Parent Needs Help*, and her free online workshop, *Memory Loss and Safety How to Have Better Talks and Fewer Fights with Your Aging Parent, Even if They're Resistant*, visit her website. Betterhealthwhileaging.net

Rosanne 53:17

I hope you enjoyed our podcast today, head over to Daughterhood.org and click on the podcast section for Show Notes including the full transcript and links to any resources and information from today's episode. You can find and review us on Apple podcasts or anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at Daughterhood, The Podcast and on my blog HeyRoe.com. Feel free to leave me a message and let me know what issues you may be facing and we'd like to hear more about or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music the instrumental version of her beautiful song *Mama's Eyes* from her album *Lessons in Love*. I hope you found what you were looking for today. Information, inspiration, or even just a little company. This is Rosanne Corcoran. I hope you'll join me next time in Daughterhood.