Episode 23: Caring for a Senior Loved One – Navigating The Healthcare System



Note: This is a machine transcription. Please excuse any punctuation or other weirdness:)

Intro:

While family caregiving can be a genuinely rewarding experience, caregivers often face common challenges that leave them overwhelmed, anxious and/or intimidated by their duties.

This could be:

- Managing their time. Caregivers often find they have less time for themselves and other family members.
- Emotional and physical stress. 22% of caregivers report that their health has gotten worse as a result of caregiving. Caring for chronic conditions like dementia or Alzheimer's disease seem to cause the most emotional stress.
- Financial strain. Because most family caregivers are unpaid, they can start to feel some financial strain, especially when caregiving takes them away from a paying job or they are taking on the full financial burden of providing care for their senior loved one.
- Being afraid to ask for help. Many caregivers feel ashamed to ask for help from others. They feel they must assume the full caregiver burden as that asking for some assistance may be a sign of weakness.
- Depression and isolation. A family caregiver is often at high risk for depression.

 Oftentimes, caregiving duties take up so much of their time that they no longer maintain social connections outside of the home.

It's important to seek a balance between caregiving and your own life.

More than 65 million people, 29% of the U.S. population, provide care for a chronically ill, disabled, or aged family member or friend during any given year and spend an average of 20 hours per week providing care for their loved one and this number will only increase. Should you find yourself in this situation what are the best options for you...

Get Savvy...Demystifying Healthcare – 30 second commercial

Are you tired of the high cost of healthcare? Are you overwhelmed trying to navigate a complicated healthcare system?

Welcome to Get Savvy...Demystifying Healthcare weekly podcast where we take complicated healthcare topics and make them simple.

Imagine if you could stop feeling paralyzed with fear and frustration and instead be empowered to make smart healthcare decisions for you and your family.

Get Savvy with your host, Sandy Kibling, a healthcare professional changing how healthcare knowledge is shared.

What we will discuss:

- 1) The top 3 mistakes people make when starting to care for their loved one?
- 2) How can care givers best navigate the healthcare system?
- 3) Key tips for care givers of senior loved ones...resources and finances.

Sandy

Hello everyone and welcome to Episode 23 Caring for a Senior Loved one – Navigating the Healthcare system. We know it is hard enough to manage our own healthcare with the expense and savvy it takes to maneuver through the system, then add the care of a senior loved on top of that..well it can be complex to say the least.

I am delighted to have Jenny Kenderes on the show today. Jenny founded Premier Senior Solutions after working in healthcare for 25 years. She is passionate about helping seniors and their families. Jenny is a motivational speaker, author of an online course for families, and a 2023 Bridge the Gap National Ambassador and has served on various panels and been awarded employee of the quarter. Jenny lives in Cleveland Oh and is the proud mother of a 22 year old son and 13 year old triplets.

Jenny welcome to the show!

Jenny

Thank you so much for having me. I'm so excited.

Awesome. Well, you and I had talked initially about my own experience in caring for my father in law, and I thought, well, how hard can it be? I work in health care every day, I thought I got this, but I didn't.

It was really challenging. I was hoping that you could share with us the top three mistakes that people make when starting to care for their loved one?

Jenny

That's a great topic, because like you said, we all think that we're prepared for this, even if we work in the industry, and then when you're hit with it personally, it's like, oh, no, what do I do?

So I love that you asked, because I do tend to see the same mistakes over and over. I think that the three most common ones that I see is because, of course, none of us want to think about our parents getting older, our spouse is getting older. So we're just not prepared.

1) We don't have the proper documentation in place, power of attorneys drawn up, and we don't even have a lot of time to handle on all of the assets or where they're located.

My clients will say, Oh, gosh, there's like 10 bank accounts I wasn't aware of. So just having that initial conversation is so important with family, especially with challenging family dynamics. So definitely that is the one thing that I see. Affairs aren't in order.

So just even if it's a general overview, it's good to know. That's definitely time consuming and a mistake that is very easy to avoid if you prepare in time.

2) I would say the other thing is to not understanding the types of care. I know, Sandy, you and I spoke about this with your own experience with independent living versus assisted living versus nursing care. It is very hard to keep track of even for us in the industry and who pays for what and what does this mean and part A and part B and when do you move, when do you not?

So it's really very complicated and people use terms interchangeably and have a preconceived notion of what those all mean. So I think that's something that is a big mistake that really can be delve into a little bit more. And then honestly, especially, this is something that I see every single day is because we all do it.

3) We're all by human nature, we all Google things. So what happens is I see if someone's starting to look for maybe senior living or even home health, they'll get on the computer and they'll Google.

But what happens is you may think you are talking to somebody local, but just the way the search engine optimization works, your name is collected in this huge national database and your information is farmed out everywhere and you're inundated with calls, and it just makes everything so much more confusing.

Sandy

Well, you hit on a lot of key things that we make the mistake of and really talking about the difference on assisted living, versus independent living. I think we jumped into it thinking, oh, my gosh, we know what's best. My husband obviously knows his dad, and we thought that was great. But what we missed, was making sure... and I'll use my father in law's name, Ron and just making sure that we knew where to start before getting him assessed at the doctor's office.

I forget the name of the test, but the memory test to make sure that we knew where he was at so we could determine, okay, what is independent living? What is assisted living?

So we could determine the best place for him because we ended up in an independent living facility and you and I talked about this as well. He had 45 ER visits. He just couldn't manage it and it cost us a fortune in health care dollars but we took a misstep there.

So would you agree that starting step one, getting assessed, and then step two, once you determine maybe it's assisted living, what is the right path to take to get to the right source to help you find the right place for in this case for a loved one?

Jenny

Absolutely. Because even when you determine maybe independent living versus assisted living, those communities all look very different as well. Then some assisted livings can handle a very high acuity of care. Most of them can. But then some there are certain things they can't handle or payment restrictions.

There's such a wide range even within their own genre of what is appropriate. That's really where somebody like myself or another advocate is really important to help because it's just very overwhelming.

Sandy

It is. So what do you do when you sit down with someone? So they reach out to you and you help them understand the differences in the facility and do you take that consultative approach where you understand the needs of the parent and then tie that into maybe options that may be best for that senior loved one?

Jenny

Absolutely. Just everything to your point. That's exactly what I do. I try to make it a very personalized approach because this journey is different for everyone. What worked for your father in law and what his needs were is certainly different than maybe your next door neighbor.

What I do is, I meet with families and we talk about things like logistics and finances and of course, clinical needs, but I'm also very big on social and emotional needs as well. I want everybody to really fit in the best scenario for them and what is going to give them purpose in their day and as well as, of course, all the other things that I just mentioned.

So after getting a sense of what everything looks like and anticipating what future needs might be, whether that be clinically or financially, I'm able to narrow down the communities that we tour together. Then I help them with the process, even if it's ancillary services, getting that together and physician paperwork. Having worked in assisted living communities, I know the back end too, and I'm really particular about the ones I work with. So I try to help them every step of the way, even if they're not quite ready for senior living community, and arm them with resources and do the best approach for them at that time.

Sandy

I love what you said about the social and emotional because I think, and again, having been through it. We were just trying to get the best care but one of the things we had a misstep on was, Ron was initially with my husband's brother, and they just had a lot of missteps and they were trying to bring them into their home. Ron had an independent life before and he didn't want to come into someone's home with their rules, so it became very chaotic.

And then we get Ron and we felt incredibly guilty putting him in a home. It's hard when you are putting him in a home because there's this stigma of...My God, you're just trying to offload your senior loved one, and that wasn't the case at all. We were trying to allow us to have our independence, but also allow Ron to have his independence as well in a place where he could thrive.

Jenny

Oh, it's so important and you literally took the words out of my mouth because so many times, those feelings of guilt that you went through with Ron, that's what all of the families go through, essentially, because like you said, there is a stigma still.

There's a misconception that senior living communities are not like what our grandparents and their parents were used to. I mean, that was a very institutional clinical setting. It's very different now and you're right, residents can thrive.

When I worked in a community, I always felt very honored to work in the resident's home and treated it as such and a good community will do things to help keep residents independent, and still encourage their hobbies or activities and they can come and go as they please.

So you are 100% correct. It's actually a better way for everyone to thrive and maintain their quality of life. It's just that guilt that overtakes us.

Sandy

It does. And I remember when we were interviewing homes for Ron, I remember one of the staff members said to my husband, it's time for you to get back to being a son and not a caregiver and rebuild a relationship, because there was some rebuilding of the relationship between my husband and Ron. So that was really amazing to hear those words.

Jenny

It really is profound because I think a lot of times the lines get flared very easily between caregiver and child and whatever the relationship is.

Sandy

Now, one of the things you talked about, as well, is the best approach for finding care. I talk about this all the time in the podcast is we're navigating our own health, our family, our kids, and now we have a senior loved one.

I mentioned our research, which adds a whole different layer. In our case, Ron is a veteran, and so we were having to navigate the VA, Medicaid, his Medicare Advantage. We're not at that age yet where we're looking for Medicare Advantage plans so we spent hours on the phone.

So what are some tips or advice that you would give on taking this approach of how to navigate to figure out what resources or out there to help us take care of a loved one from a financial perspective and, of course, keeping our sanity along the way.

Jenny

Right. You're absolutely right. I get very frustrated for my clients and seniors because even with the best intentions, maybe physicians or hospitals, they pass along inaccurate information as well. So especially because it's like you said, if there's the VA or Medicare, everybody's situation is different.

If there's a trusted advocate, whether it's a senior living placement specialist like myself or an elder law attorney that you trust, somebody that can help guide you through just even the very basics. Not everybody should be given the same blanket option...do this, spend all your money. There's so much more than that. So I would say really try to have somebody in your corner, maybe somebody that's been there before, even if it's a friend or a neighbor. Of course, their situation, like I said, will be different, but at least they might have some guidance.

Truly, what I try to do with my clients, too, is steer them in the right direction. There's so many programs, especially when you mention the VA, that people aren't even aware of. They aren't offered these solutions. They're like, Why have I never heard of this?

I try to be a plethora of resources. There's things like the Alzheimer's Association, and different online sites. I have a Facebook group that I try to keep putting information and caregiver support group.

This is also why I did my course. The more information we can be armed with, the better off everything's going to be. And to your point also about keeping our sanity, I think it's really important for us to recognize our quality of life, how it may suffer, a caregiver burnout is really real. And the self care that needs to be done for us as well.

Sandy

That is so true. One of the things that I think comes to mind is that it's so great to have resources like you out there that have that expertise and have that passion and willingness to help us.

You talked earlier about the search engines, and I've seen commercials, a place for mom, and I'm sure all these organizations, people are trying to do good. But I'd love to hear more about your firm and how you're helping people and what makes you different?

Jenny

Thank you. I know I shared my back story a little bit with you. I had worked in senior living and health care for so many years, and I was frustrated even working in senior living because I would see some of the larger organizations send a referral my way. I felt so bad for these families because I'm like, they aren't qualified, really, for this community. They either have a diagnosis that they don't belong in here, or they will run out of money or whatever the case, and it just wasn't ethical. And I kept thinking, I can do this better.

I really want to be there for families and not just give them a name of a community, and not knowing anything about it. A lot of these companies aren't even local to where everybody lives.

So being a single mom I was very afraid, but I finally pulled the plug because I felt like my purpose was really to help everyone. And I am there with them every step of the way. I don't strive to be a place for mom or any other massive company that has 50 move ins per month.

That's not what I want. I want to maintain my integrity and I want to be able to help families from start to finish. And whether that be sometimes, and I'm sure you can relate, sometimes it's a very long process. It can be a year or two. It can be a very quick crisis mode move where somebody's like, I need to move tomorrow, and that's okay.

Wherever they're at, I'll meet them at and do the best for them. I've literally packed up my car to help people move in a pin. I offered to fly down to Atlanta one time to pick up a client. She didn't have anybody to bring her back. So whatever needs to be done, I always want to try to offer that red carpet service because it's so overwhelming. Then well after moving as well, I want to make sure that things are being done at the community as promised.

You're getting your care conferences and all other amenities even if it's the tiniest thing, it could be something so minor and somebody doesn't want to say something, come to me, I will be the advocate still.

So I really try to help every single step of the way and ensure everything is as it should be.

Sandy

I think that's so important to have an advocate help you with, for, placement in assisted living or independent living. I like what you said about that red carpet service because it's everything else in between. Especially when you're thinking about, gosh, what can I do? It's really nice to have that A to Z approach that you provide and really that trusted source. And it just touches my heart of what you said about reaching out and going that extra mile to pick somebody up or whatever. I think we all just need to lift each other up with kindness these days.

Jenny

Oh, my gosh. Absolutely.

Sandy

Let me ask you about this, because one of the things that is probably top of mind is we all know finances, and that becomes an extra burden. And maybe in some cases, maybe a senior loved one has set money aside.

I know in our case that wasn't. We had Ron's, I believe, his Medicare or his Social Security, I should say, but that's not much. And so as a family, we do what families do. We all come together and we try to help. but that can be such a burden. Do you help families to see what resources may be available to them as part of your red carpet service?

Jenny

Yes. And I love that you said how you and your family were coming together for Ron, because that's truly such a blessing because so many families don't even offer that. So that's wonderful. But yes, I do. In fact, because, again, everybody's situation is so different, like you said, somebody may just have social security, or somebody may have millions of dollars. Not that we want to spend it all, but I really try to help them stretch out their funds and see, okay, this is what realistically can be afforded and for how long.

And if it's a situation where they have a house to sell, take that into consideration, and maybe it's not too late to recommend irrevocable trust or an elder law attorney. There is also that look back period that Medicaid and the VA does. So I'm cognizant of that as well. But based on what their situation is, I want to make sure they're set up.

So if it's a community that we need to look at that will accept Medicaid payment, Medicaid waiver, there's different types of Medicaid in a year or so, we're going to go in that direction. Because the last thing I want anybody to have to do is move again, especially if there's a cognition concern.

I mean, that can lead to more of a decline. So I absolutely help them find programs, look at their assets, look at ways to stretch it out, negotiate on their behalf if need be with the community, and just make sure they're set up for success. I think that's the most important thing.

Sandy

Yeah, you know what you said is so important, too, and when I think about getting it right the first time. This is me having to look back of what we did wrong and what we should have done right.

I think about this because we did have to uproot Ron. He was an independent living, and he does have some cognitive issues and memory and a few other issues. But he was very, very upset to move, and it was just a very, very complete stressor for all of us. We finally got him calmed down, and thankfully, he's now in assisted living, which is where he should have been to begin with. But again, we didn't know, but he's doing so much better. So I think that moving part of it is so important to make sure that you get it right the first time because it can be time consuming, stressful, costly, and all of the above. I think I mentioned,

I was going to ask you about this, too, because you mentioned researching facilities, it sounds like you have a great connections. I think the fear that we have as caregivers is what if I put my loved one in the wrong place?

One of the things we talked about as we thought the independent living place was great, and we thought we paid somebody for Ron to get his medications, and turns out they weren't giving him medications and he ended up in the ER, I mentioned earlier, 45 times. Do you keep eye on these facilities, because anything can happen, but making sure that that independent or that assisted facility is safe and there's checks and balances.

Jenny

Yes, that is such an excellent point. Yes, we are in a challenging time coming out of the pandemic and staffing shortages and things like that, but there are some buildings that have done great jobs and they don't use agency and things like that. Yes, I am extremely particular. I do have contracts pretty much with all communities, but that doesn't mean I refer to them.

I think I shared this with you, too, that community could be great, maybe six months ago, and it could be something like a leadership change, or it could be the slightest difference, and it's not so great then. Communication is just as important as care. So I really do stay on top of them. And in terms of the checks and balances system, I send an annual Key Performance Indicators (KPI) report to the communities, and a lot of it is based on family feedback. But I'm always checking in, like I said, with the families, the community, making sure they're getting their care conferences. I would lose sleep. I mean, I really would lose sleep at night if it's something that I thought was not right, I would really have a hard time.

If I would not suggest a community for my loved one, I certainly would not suggest it for anybody else. And like I said, with a lot of the changes and mergers and things like that that are constantly happening in this industry, I really do stay on top of it. The facilities know that. They know I hold them accountable, not in a mean way. They know that I like to know what's going on in staff changes, and they know I'm going to find out if you will. But it's, again, to protect the residents. So that's a great point.

Sandy

Yeah, no, that is true. And you're right. I see it in my physician consulting job all day long, the changes that go on. So nice that you do that part. I'm going to put you on the spot. Do you have a story that you can share about a family that you've helped and their journey and outcome?

Jenny

Oh, my gosh, so many. I'm trying to think of one of the best ones. Okay, I'll share one. Sometimes the most gratifying is through, unfortunately, crisis mode for the family and they don't know what to do. And it was right before the pandemic.

It was the day before Thanksgiving in the hospital. One of the hospitals here in the area had called and they're like, this... It wasn't even... So there was a lady taking care of somebody that was living at home with her, and it wasn't the elderly resident that was in the hospital. It was her caregiver. She couldn't be at home to take care of her. And she's kept saying, it's the day before Thanksgiving. I don't know what I'm going to do. I'm going to be here for weeks.

I had an initial conversation with her and knew that it was going to be a memory care situation for her friend that she was taking care of. So a really good community that I know is just like, What do we have to do? All hands on deck here. They're great to work with. We jumped in the car, met at the hospital, did a quick assessment.

We went to the home then, the caregiver's home, packed her up. I don't even know how we pulled all this off because there's the trends and physicians have to sign off on things. Normally, we can do things pretty quick, but this was before a holiday. We were at the physician's office then, waiting for the paperwork, and literally putting her in our car and getting everything done.

Just to give not only this poor lady in the hospital some peace of mind but that her loved one was taking care of. We got the furniture in really quick and I think the state was in there, too, doing their annual inspection. It was just such a collision of all these events.

Then we ended up finishing up Thanksgiving morning, and she was able to have Thanksgiving dinner at the community. It was one of those things you just rally and support. You just do it. You just jump into action. You have to do it. So yeah, that was a feel good story, being around the holiday, and resources were a little bit limited, but we did what we have to do.

The notes you get and the emails, I mean, those are the things that fill my cup up. It's just the things people say. One gentleman wrote on Facebook the other day, you've changed my life and you saved my family. I'm like, Oh, my gosh. That's what keeps me going every day, those things.

That's such a great story. You talked about the collision of events and working on things so quickly. You have that expertise and that knowledge.

If that just happened, say to me and my husband, we'd be like, Oh, my God. Where do we begin? So it's always nice to have that expertise. That is such a great story and helping out that family. I appreciate you sharing that.

I know that you have also a wealth of resources and stuff on there. And I wonder if you talk a little bit about, I think you mentioned about an online course that you have for families because, again, I always talk about knowledge is essential in navigating the system. It's key to be your own advocate, or in this case, an advocate for your senior loved one. Can you tell us a little bit more about the course?

Jenny

Absolutely. This was two years in the making, and I could have not done it without a whole creative team behind me especially the technical component. But I always knew that... And you find this a lot, too, we're constantly educating on the same things because people aren't aware of things.

It doesn't matter where in the United States you live, the basics are pretty much the same. But again, it's not having that information. I spent two years creating a course for families and in this online module, it's everything from caregiver burnout, what to look for with dementia, how to choose a senior living community, and everything in between. Hospitality, home health, Medicare, everything just all wrapped up in one nice package.

It's on my link tree also, and there's a free downloadable version, like a mini free course for everyone that they can grab as well, too, with just tips on falls and things like that because it really is so important, and that information is available at your fingertips whenever you need it. And some people pay... Geriatric specialists are wonderful, but some people are paying thousands and thousands and thousands of dollars for this information. I'm like, It should not be that difficult. So, yes, I was very proud that it took a long time, but it's there.

It's great resources. It's literally everything A to Z. And there's extra little bonus features and things like that. So I'm really proud of it.

Sandy

That's fantastic. Well, I'll make sure we add a link to that in the show notes so people can check that out as well, because it just starts with knowledge. I think we have this tendency to race into, what we need to do to care for that loved one. I know that you talked about the earlier collision of stuff. I remember when we got Ron.

I live in Denver, and it was in the middle of a snowstorm. My husband was driving across the US halfway to meet his brother in a Mustang in a blizzard.

We know how well those do in the snow, right? Not recommended, let me tell you. But once we got Ron home we're just like, oh, my gosh, we thought we did the right research but we didn't. I I like that your course has those things that just gives you that knowledge, that base, and probably things you didn't even think you needed to know. So that's super valuable.

Jenny

Yeah. No, you're right, people don't necessarily understand even that you can be on hospice for so many years. It's not just end of life or there's different life management tools and things that I include on there, different apps, anything to really help because like you said, there are so many different options that people wouldn't know about otherwise.

Sandy

Yeah. No, that's fantastic. Well, this has been such a great conversation. I wanted to leave it to you with some closing thoughts and or recommendations that you wanted to provide the listeners that might help them on this journey of caring for a loved one.

Jenny

Absolutely. Thank you for having me on because it's so great, Sandy, like you said, you've been through this, so you understand firsthand how much of a challenge this is. I think right now, we're seeing more and more of the sandwich generation. It's our generation, aging parents, and we're also trying to take care of kids or grandkids, and it's really hard.

You're managing everything, and it's even more stressful for everybody. So things can get very overwhelming very quick. And it's also very hard if you have an aging loved one. I think just some of the biggest things I could say in closing, it's a journey. And number one, self care, we have to take care of ourselves. We have to have some patience. I love talking about the dementia journey and ensuring their reality and things like that because that's a whole another subject for another day. But it's relearning a lot of things, and I would also say, just stay on top of your loved ones. I mentioned earlier some of the pieces like the power of attorney and things like that and make sure if they're living at home, the home is safe, the medications, check for little things like are there expired foods?

Is there damage to the car? Little clues that if they are living at home, you can start to keep an eye out for these things.

That's fantastic. I love what you said about the self care and also it is a journey, as there's so many moving parts. I think what we talked about earlier as well as a closing thought, is just recognizing, you're taking away that independence in some way of that senior loved one, but you're trying to find that next step for them that allows them to be as independent as they can be and to live their best life with the years they have left.

Jenny

I couldn't have said it better myself because the alternative, unfortunately, is if you wait too long, then your options are very limited, unfortunately. And they don't have the pleasure of partaking in that decision making with you. So well said.

Sandy

I think the message here is always this has been great. Navigating the health care system, and I say it all day long, but you're not alone. There are resources out there and people like yourself that are willing to help people on this journey. You're absolutely right. I don't know what the statistics are, but I'm certain that either there are many of us today taking care of loved ones or that will be the future for many.

Jenny

The silver tunnel is coming.

Sandy

Definitely. Oh, my gosh. Well, this has been great. I'm so grateful for your time and your expertise today. I appreciate you being on this show. Thank you. Absolutely.

Wow, it was great having Jenny Kendaris on today. She provided so many helpful tips when it comes to caring for that senior loved one. I'll make sure and provide those resources in the show notes so you can take a look at these resources.

This is the start of our guest series. One of my promises has always been to make health care knowledge easier to understand by sharing stories. I have a series of individuals coming on telling their stories that I hope makes it easier for you to navigate the healthcare system no matter where you are akin your healthcare journey.

Until next time Get Savvy!