

Recognizing the Role of Caregiver

With Melissa Fisher

Episode 79

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Melissa (00:00):

Post-discharge, now there's where I felt like I was dumped. When I was in that experience in that hospital, it was fantastic. But the case worker, the social worker, they all go away the minute the transfer happens. For me, I went from a peak and a high back to a low, to now I get to start in on DHS and Medicaid benefits. Again, a myriad of paperwork. Where can we formally think about the journey and start putting some things in place to make that journey more clear, understandable, not only for the patient, but that caregiver?

Speaker (00:41):

Welcome to The Healthcare Leadership Experience podcast, hosted by Lisa Miller and Jim Cagliostro. Lisa is the founder of VIE Healthcare Consulting and is now managing director at SpendMend. Lisa and her team has generated over \$1 billion in financial improvements for VIE's clients since 1999.

Since 2007, Jim has been a registered nurse working in critical care, perioperative services, and outpatient settings at nationally recognized medical facilities across three states. You'll hear conversations on relevant and trending topics in healthcare and much more. Now, here's your hosts, Lisa and Jim.

Jim (01:21):

Hi, this is Jim Cagliostro, and you're listening to the Healthcare Leadership Experience. Today's guest is Melissa Fisher. She works in communications and the consumer experience for one of the largest health systems in the country. She's here today as a guest. Yes, she has that experience and that under her belt, but more so as a caregiver. We're going to talk about what that means.

Today, our focus of our conversation is about recognizing the role of caregiver and including the caregiver as part of the team. So Melissa, thank you for joining us today. Welcome to the show.

Melissa (01:56):

Thanks, Jim. I'm really happy to be here today with you.

Jim (01:59):

So I always like to start, again, you work in healthcare, so you have this perspective, but I like people to know who we're talking to. I know today you're really coming from a point of your personal experience, and so maybe share a little bit about yourself, what you do, but also why this topic of caregiver is so close to your heart.

Melissa (02:19):

Absolutely. Aren't we all many things?

Jim (02:23):

Yes.

Melissa (02:24):

I'm daughter, I'm mother, I'm wife, friend, all of those things. But just to give you a little bit of a background on me, I'm married. I'm a mom of two. My kids are grown in slow-ish, I like an -ish there. My daughter's in college, a sophomore studying public health and business.

Jim (02:43):

Okay.

Melissa (02:44):

My son recently graduated with a degree in civil engineering and starts in a couple of weeks. That is a big career. So I'm really excited for that. I love to run and ride my bike when I can find the time. My husband's a personal trainer, so some of it is motivated by the fact that he is really big into this stuff and I just like hanging out with him.

Jim (03:06):

I like that.

Melissa (03:08):

Thank you. I was a retail consumer experience consultant, and I did that for many years. Then I transitioned into healthcare. I worked for the last 10 years, like you mentioned, for a large healthcare system in communication strategy. My focus is on care experience. My thoughts and opinions today that I'm sharing are strictly my own, but it is interesting. I am a hybrid. I am somebody who has a lot of lived experiences and working on both sides. It's really helped my work, and I believe, hopefully, it'll benefit your audience today. My lived experiences thrust me into my life's purpose.

Jim (03:47):

Sure.

Melissa (03:47):

I'm an active volunteer and a passionate advocate for dementia and caregiver rights. I'm an ambassador for the Association for Frontotemporal Degeneration. I'll go into that a little bit. Through my work, I hear the stories of many people who are caregivers for their loved ones, and most of them involve systems that let them down and even made things harder for them.

Melissa (04:09):

So why caregiving? I'm a caregiver/care partner that treat people. For my parents, they live remotely, 3000 miles away. Also, my aunt, who is local, I would tell you, my mom does not see herself as needing any care or identifies me as a care partner. I always say it's complicated, and I think that's part of what we'll talk about a little bit more today.

Jim (04:35):

Yep.

Melissa (04:36):

I'm not a caregiver. My dad, like I mentioned, has a behavioral variant of frontotemporal dementia. My mom was diagnosed last July with Parkinson's, and I'm seeing executive function challenges. Then my aunt, the most recent in my suite of people that I help, was identified as having uncategorized dementia with psychosis.

It's all been made more challenging by not feeling like I'm seen or recognized by organizations and systems. I have experienced barriers. I've watched my own mom's rapid decline after years of being my dad's caregiver, and I keep having to ask myself, "Can't we do better?" That's really what it's at, is this question of, "How can we do better?" And I think there are a lot of great opportunities to do that.

Jim (05:31):

I know I mentioned to you this previously, Melissa, but I believe the conversation today really will speak to so many people on a personal level.

Melissa (05:41):

Yeah.

Melissa (05:41):

You've shared, it's not one system's problem. This is a broader healthcare issue that we want to see addressed for the sake of patients and for the sake of those who are caring for them. So I think maybe to get down to the basics,

how would you define the role of caregiver today? And maybe more importantly, why has that role changed in recent years?

Melissa (06:04):

Yeah. You're right. It's not one system. We touch everything or we get smacked by many things,-

Jim (06:11):

Right.

Melissa (06:11):

... sometimes all at once. It's a giant slap. So I've been thinking a lot lately about how different it is from when my parents were involved in their parents' lives. For one, they weren't raising kids anymore. My mom and dad had me in their early 20s. I was already well established, had kids of my own, working full time, and my grandparents when they began to have problems or issues that needed help. So uniquely, there's this thing now called the sandwich generation. I'm at the tail end of that,-

Jim (06:41):

Okay.

Melissa (06:42):

... but it feels less like a sandwich and more like a panini press at times.

Jim (06:47):

Okay. An analogy, I like that.

Melissa (06:48):

Yeah. It's not mine. I can't take credit, but I use it quite frequently. We can't ignore the silver tsunami. The boomers are here, which makes me wonder, why are we just now talking about this? It's been good to have this conversation 20 years ago.

Jim (07:04):

Right.

Melissa (07:04):

It just feels like all of a sudden we're all looking around and going, "Oh my goodness. We've got a lot of people who are needing care." And we also used to live in close proximity to one another. My parents, they moved away when I graduated and pursued their lives where they wanted to be. So I understand it, but we're spread out more.

Jim (07:24):

Yes.

Melissa (07:24):

Kids move from rural towns. They're going to other parts of the country to make their way. They aren't staying in the homestead anymore. We also are having children later. My parents were able to save more, and many of them had homes. Americans are also, as I'm starting to realize, fiercely independent, and that's part of the problem because my mom sees her position as if I am there and helping her, then she is losing her privacy. She wants to maintain her own home. But I think back another generation, and my great-grandmother lived with my grandparents all under one roof. They helped with the raising of the children. So it just feels like there's been this shift in who's caring for where.

Jim (08:13):

Sure.

Melissa (08:13):

People are living longer, but not necessarily better. Half of all caregivers who helped older adults do so for someone living with dementia, and 83% of those are family members, and many of them are still working.

Melissa (08:29):

So for me, back to the question of why has it changed? I'm not even entirely sure, but I have been very focused on looking at all of the different factors that have brought us to where we are today. Those are just some of the top ones that make me think that's so different about now versus a generation ago.

Jim (08:52):

I think what you're saying really speaks to a lot of people. I know I've shared with you that whole sandwich generation, we have children down to a one-year-old, but also beginning to care for my mother, who has memory issues.

Melissa (09:04):

Yeah.

Jim (09:04):

So it is challenging, and like you said, there's multiple factors, and times are different. I really didn't think much about what you shared, the geographic, the distance, because people really do live further from family. So yes, many factors, and thank you for sharing that.

So I know I mentioned this, and I know you can speak from the role that you have in your health system, but we've also talked about how our personal experiences inform us. You've touched on that already, but what would you say are some of the challenges that caregivers face today based on both your professional experience, but probably more so, your personal experience?

Melissa (09:42):

Yeah, four things. Time, cost, personal wellbeing, and training and resources.

Jim (09:51):

Okay.

Melissa (09:51):

Those would be my four. Time, cost, personal health, and training or resources. Time, I work a full-time job, and it's demanding. I absolutely love what I do and the organization I work for, but I am strained to find time for it all.

Jim (10:08):

Sure.

Melissa (10:09):

I think that I'm not alone in that, and talking to my friends and reading a lot of things online. I know that time and its finiteness is that I just don't have enough of it. Also, money. If I've learned one thing, it's either I need to be extremely rich or incredibly poor. I know that sounds really blunt, but getting access to support and services for the majority of Americans right now is not feasible. If you can't afford help, then who's going to do all the work? Unpaid, untrained, overwhelmed, burned-out individuals, likely adult children, are that. I've become a bit of a cynic because I see my father in a nursing home, and my mom is paying \$12,000 a month for his care, and the person in the bed next to him is on Medicaid and paying nothing.

Melissa (11:05):

Again, I want care for everyone, but I'm also recognizing that I either need to be really well off, and then who's helping pay for college and all the other things and costs of living that are what they are? But money is, to me, a massive challenge.

Personal health stress means personal needs move to the back burner. Physical and mental health are compromised. Case in point, I've had a couple of really bad mental health situations where I was overwhelmed to the point of even causing, I don't know what you call it, stress hives from head to toe. I have felt depleted. My eating, my movement, all things have been sacrificed at some point in time. I think that's a big challenge for caregivers is how does one... because people say, "Oh, make time for yourself." When?

Jim (12:02):

Yes, that's right.

Melissa (12:02):

How do I do that? It's not spa days. Respite,-

Jim (12:04):

Easier said than done.

Melissa (12:06):

... sitting in the car between things and just taking deep breaths, training, or lack thereof, this is truly an on-the-job training experience. By that, I mean trial and error. So when I have... My father was who I cut my teeth on, my father with his FTD, that's the shorthand for frontotemporal degeneration. I had no experience with this. Of course, I had to cobble together who would be able to help me. A lot of Googling, a lot of just trying things out on him to see how things went, but reality is, finding what I needed was ridiculous.

Melissa (12:50):

So I think a lot of caregivers don't necessarily know where to start or what to get help with. The places that you do get help are the most unlikely of places. It is not the doctor's office. It is not among upon discharge from the hospital. It is typically much campier and maybe a little less structured, and you're always trying your very best. But now that I'm on my third assignment, I'm getting a little bit better. But that's why I advocate, and I volunteer as much as I do, because I would like other people not to find getting information to help them be a caregiver as difficult as I have.

Jim (13:31):

You mentioned, I want to say those four things again. Time, cost,-

Melissa (13:35):

Yep.

Jim (13:35):

... personal wellbeing, and training and resources. Maybe for one, it might be the time issue. For another, it might be the personal wellbeing. All four, I think, are extremely valid, but some might hit closer to home than others. You mentioned that it really has become, it's a trial and error and we don't want it to be that. So we're going to get into that in the second part of the conversation. But I love everything you shared there.

Jim (13:59):

If you're just tuning in, you're listening to the Healthcare Leadership Experience, and I'm your host, Jim Cagliostro.

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Jim (14:32):

So Melissa, I loved when you said this. The last time we spoke, you mentioned to me that we need to view families as part of the care team. That stood out to me. I wrote that down when we were talking. We need to view families as part of the care team. How can hospitals, health systems, physicians, other healthcare professionals help caregivers face those challenges you just shared and really make them a part of that team? Not just make them feel part of the team but make them a part of that caregiving team.

Melissa (15:01):

Yeah. This is the core of what I really want to communicate to your listeners today.

Jim (15:09):

Please.

Melissa (15:10):

Okay, here we go. Get us connected. Think of us as a unit. When my father was diagnosed with FTD, finally, after three years of trying to get help and a diagnosis, I started saying, "We all have FTD." Often, how we come into your systems is events. It's initiated, not as a preventative or proactive planned thing. It's usually crisis.

Jim (15:43):

Sure.

Melissa (15:44):

I read something the other day that really hit to the problem that ends up in our emergency rooms. 75% of families have been about their needs with their older family members. As a result, they're showing up in the ER, and now the talk needs to happen. Believe it or not, these moments of crisis in the ER are often the first time that things are being discussed.

Jim (16:09):

Yep.

Melissa (16:11):

So that's a case in point, and I'll share a little story about this, but I would say that before we end up in your ERs, our primary care providers have an opportunity that needs to be formally presented. That is conversations with their elder patients about what they do when something happens and get them set up to make sure that someone is supporting them. One of the biggest issues that I'm facing right now is that I don't feel connected to my mom's care.

Melissa (16:46):

When she goes in, she goes in the morning, she spends 2.5 hours getting her hair and makeup done, and she does her very best to show time. That's a term that a lot of people know about, where we're going to show up and we're going to show that doctor, I am fantastic.

Jim (17:05):

Yeah.

Melissa (17:07):

Really, they're not. But if you start checking the boxes, do they have POA? Is somebody on their medical? Are they proxied? Are they part of the electronic health record? When your disease progresses, what plans do you have for your housing? You mentioned you live in a two-story home with no full bath on the first floor. What are your plans? I think these talks have to happen with the patient much sooner. I think that it has to be a part of the formal exam. I don't necessarily think that's happening because every time I try to have these conversations with my mom, I feel like we're talking about asking her to go relocate on the moon.

(17:57):

Yeah.

(17:57):

That's true.

Melissa (17:58):

Let's just go to hospitals, though, for a second.

Admission needs improvement. Like I mentioned, a lot of older adults come into the hospitals through ER. So I'll share a story.

(18:08):

Please. Yeah.

Melissa (18:09):

My dad had FTD. The year was 2020, and it was February 2020. My mom had been taking care of my father at home for many years, couldn't find a place for him. It had taxed her so much. So the week that we finally found a place to place him, he wasn't doing well there. I took her away for a short escape to a local hotel, and I wanted to give her the pampering treatment that I felt she deserved while doing a yoga pose at a beachside exercise class in the resort. She fell over, and the top of her femur snapped off. At least that's what we found out later when I followed the ambulance to the local hospital.

Melissa (18:57):

Interestingly enough, up until that moment, my mom had told me, because I lived so far away, that nothing would likely happen while I was with her and I'd be too far away. So she didn't see any value in getting me set up on her medical forms and really being able to help her. I'm driving behind this ambulance, and my dad's in a skilled nursing facility, doing really bad. Mom is now on her way to the ER. I had to, when we got to the ER, they had to scramble to find a social worker to get forms that I would need so that I could advocate for my mom. They were holding off morphine so they could get her to sign the paperwork. I'm like, "How did we get here?"

Jim (19:43):

Yeah.

Melissa (19:43):

That's what I kept asking myself. She needed emergency hip replacement surgery, but now the ER was at the center of this chaos. I felt like in that introduction, things were very clunky. They had nothing on file. So if they put her under, where was I in this? How could I help her?

(20:06):

Right.

Melissa (20:07):

During this stay, we'll move to that. No one was really talking to me. My mom was coming out of anesthesia, and she was on a lot of pain medicine. Having just had her hip replaced, and her short-term memory was a disaster. I had to leave the hospital at times to help my dad and also try to prepare things for her. But of course, that was always when the doctor rounded. I think it's ironic, like you wait all morning and you wait and you wait, and then all of a sudden you're like, "I really got to go deal with this." And so you leave. Of course, it was when you were gone for 20 minutes.

Jim (20:42):

Yep, I know that.

Melissa (20:43):

Then you have this fun game of piecing together what I am supposed to know. What am I supposed to do? What are the medications I need to get? And then many times my mom just said, "I don't remember. He said, I'm doing great." And I'm like, "Okay." That was interesting. Then hospital discharge, that needs improvement. It needs to include the caregiver, especially because you're either going back home or to a skilled nursing facility or rehab of some kind.

Melissa (21:10):

Those transitions in care have me thinking, "How can you just discharge her?" And it was very fast, like rapid fire. They wanted to get someone else in the bed. I remember at the time that the hospital she was at was really having a lot of need for beds, so they were fast, but the discharge papers were 74 pages long and didn't really tell me what I needed to do or what do I do now. I was thinking about when I was discharged after having my baby, which is a long time ago, but I got loads of help, classes beforehand, and follow-up. Why is the beginning of life so well-orchestrated, but the end is not?

Jim (21:54):

That's a great point.

Melissa (21:55):

Why?

Melissa (21:57):

I know that there was a hospital survey. Because of work, I read these things, it found that 60% of falls happened at home. So what do I need to know or do before I can safely be bringing her back home? And then the case managers, the social workers, they all go away at discharge. That happened with my aunt, and that's when I need the help the most. So with my aunt's admission, she went to four ERs in 10 days, and none of them would admit her. I was desperate to know what was going on with her. I begged the final hospital because there were four different systems. In 10 days, you'd think we had one.

Jim (22:37):

Oh, wow.

Melissa (22:38):

I should get a free pizza by the end of that.

Jim (22:41):

Emphasizing the point that it's not just a single hospital or system.

Melissa (22:44):

No.

Jim (22:45):

It's a broader issue that we have to address.

Melissa (22:48):

They were all using the same criteria. She had the UTI. It was a bad UTI, but they were treating the UTI but not the behaviors and the other parts, and the desperate person like me going, "Please admit her. Please help me figure out what's going on. I need to know. We need to stabilize her. She can't take care of herself." And that's even before I knew that her apartment was uninhabitable.

Jim (23:10):

Yeah.

Melissa (23:11):

So I want to know, when I am admitted, who are you? Who does what? What resources are available to me here and after discharge? What community services are there for me? I didn't know about my aunt's healthcare benefits or Medicaid or Medicare process. I had no idea what she qualified for or didn't qualify for. I didn't know her medications or the routines. Again, this has happened time and time again, and I've been to so many ERs and had so many of these experiences, it just begs the question, if this is happening so often and me not personalizing it and saying it's a lot of people, why does it feel like it's the first time this has happened? And we have to figure it out as we go, where's the playbook? Why can't we design a model for this? That's where I put my work brain on.

Jim (24:07):

Yeah.

Melissa (24:07):

Because I'm like, "I'm not unique." I am, but I'm not.

(24:12):

Sure.

Melissa (24:12):

So why is this always such a crisis? Not that it isn't a crisis, but where can we formally think about the journey and start putting some things in place to make that journey more clear, understandable, not only for patient but that caregiver? And that's back to the unit. Look at me in that room with my look of desperation, somewhat shock, and maybe even a tinge of anger because I'm like, "Mom, I've asked you this question over and over again, and yet here we are." So you're dealing with people who are under a lot of different strains. So how can that unit be recognized? Because I think that's going to help us in the bigger picture.

Jim (25:03):

I know, Melissa, that you're speaking to many of our listeners because I see myself in my situation in what you're describing. It is not a one-and-done where this is a unique experience. This is the experience of many of us, and it's challenging. You're making me think of as healthcare providers, and you named a bunch of different roles that exist within the recognized care team. How can we open that door for the caregivers, for the ones that truly are at home 24/7 with the patients?

Melissa (25:31):

Yeah.

Jim (25:32):

Open the door for them rather than having them have to go and knock on the door and bang it down and say, "Okay, I need help." We need to be more proactive. You're hitting on so many things. So I think the follow-up for that would be the motivation behind it. Why, as healthcare professionals, why as hospital leaders, should we be concerned about recognizing caregivers as a key part of the care team? What are the benefits of including caregivers? I think you've touched on that, but maybe we can... I think it'll help to actually say it and share that.

Melissa (26:04):

Yeah. First, I would say it's not only those who are in home, because a lot of us aren't in home.

Jim (26:11):

Right.

Melissa (26:11):

We're remote and virtual. That's where technology can really go a long, long way to make things better. So think about your caregiver, not just the person bedside, but the person who is calling all the time and asking for updates. Again, for every call I make is taxing your staff.

Jim (26:31):

Right. Good point.

Melissa (26:32):

If I'm trying to figure out the nurse, the morning shift nurse versus the nighttime shift nurse, and trying to help you help them, and we're having to have all these sidebars, we're likely wasting time and money. That's a cost, right?

Jim (26:47):

Sure.

Melissa (26:47):

So how can we be better connected from the moment of whatever, either it was a planned thing or an unplanned thing? So one of the things that's interesting is that there's this thing that we all know, and I'm sure your listeners do, HCAHPS. Those are those clinical quality and patient experience surveys. I want to know who's asking me about my stay.

Jim (27:10):

Yeah.

Melissa (27:11):

I felt like I was staying in all those situations, and what we don't measure doesn't matter. If we're not asking the right people many times, how can we learn if we don't ask the caregiver about their experience? We're not asking caregivers. I find that interesting because my mom in the hospital can't clearly even remember that she broke her hip and/or femur, and yet you're now sending her an after-patient survey. Then I'm looking at it, and I ask her, and she's like, "I don't know. I was on so many medications."

Jim (27:47):

Yeah.

Melissa (27:49):

Are you getting what you need to process improve? I don't know how, so I just want to call that out.

Melissa (27:57):

Then for rural healthcare systems, which my parents are in a rural place, technology, I understand is expensive, but if you don't make investments in it for the caregiver, that's detrimental. The manner in which I have to communicate with my mom's primary care provider is woefully behind. The visit summaries are vague. They're not written in a way that I can decipher what they talked about in their exams. I'm actually heading to where my mom and dad are this Saturday, and I've asked for her next appointment, which I will be present in. Please tell me what your caregiver communications plan is moving forward. I'm asking, I want to know.

Jim (28:38):

Good for you.

Melissa (28:39):

Are we having a five-minute call after mom's appointment, or are you calling me in? Or are you going to start writing after visit summaries that don't remind me that my mom wants had a caesarean section? That's the top of the notes. I'm like, "Come on, it says she's married, but it doesn't say she lives alone."

Jim (28:58):

Yeah.

Melissa (28:58):

How does that help anybody?

Jim (29:01):

Right.

Melissa (29:01):

To me, those are some of the things that I think affect the outcomes for the patients. Again, I'm trying to navigate information and figure out what that means when her cholesterol level keeps showing up really high. What have you asked my mom to do? Why is she continuously telling me she loves gelato and is eating that in lieu of dinner because it's easier? I don't want her to have more need of medications. I want her to be as healthy as she can through Parkinson's, and I want to minimize readmissions. My dad was constantly at the emergency room, and that is not good. Yet, I don't know if anybody actually took the time to kind of look at the big picture for him. As a result, mom, her health dwindled, and then it became the same hospital's problem to deal with my mom's health needs, that were very expensive and difficult, as well as my father's.

Jim (30:01):

Sure. You hit so many here in terms of when we include the caregiver, not just think about them, but we are truly including them as part of the care team, it improves patient outcomes, the quality of care. You mentioned

about readmissions. That's costly for hospitals, where we have better patient satisfaction. Ultimately, you mentioned about cost. Yes, there is the business aspect of healthcare. If we don't address the issues upfront, it's going to cost us down the road.

Melissa (30:32):

Yeah.

Jim (30:33):

So I think those are all great points, let alone, yes, the patient outcomes and the care that we're providing. That's number one. But it will cost us more down the road.

Melissa (30:41):

For sure.

Jim (30:42):

You've touched on this, but I think I want to ask again if there's anything else you want to add. There's one word that comes to mind, and I know I've brought it up. When we've talked in the past. When we talk about navigating the healthcare system and serving as a caregiver for a loved one, frustration is a word that often comes out of my mouth. It often comes to mind. There's so many parts that we can be frustrated with.

Melissa (31:03):

Yeah.

Jim (31:03):

What have you found the most frustrating? If there's anything else you want to share, I think in what we've talked about, there's plenty to be frustrated about. What has been the most frustrating, but also what has been the most helpful? Have you seen, maybe, some light at the end of the tunnel?

Melissa (31:16):

Yeah.

Jim (31:16):

Some things that are like, "Hey, there are some systems or some even local places that are doing it well."

Melissa (31:22):

Yeah. So my father. He was the most difficult in terms of care. He was constantly falling. He overdosed by mixing his medications with alcohol. He escaped the ER with IVs in his arm quite a bit, and security had to go chase him down. I wasn't there for any of that. He also refused to believe he had broken his leg on one occasion. My mom's doctor, my dad's doctor really didn't understand the extent of the problems he was having with my father. He presented in his 60s with some behavioral challenges, and they just snowballed. Eventually, when he said that he wouldn't let anybody cast his leg for being broken, that's finally when the doctor stepped in and helped my mom get guardianship.

Jim (32:08):

Okay.

Melissa (32:08):

She shouldn't have taken that long.

Jim (32:10):

Sure.

Melissa (32:11):

Because just trying to get people to believe us is a big problem. They're asking the questions of them. My aunt, when she was being bounced around the ERs, they were talking to her, but yet we're all over here shaking her head, going, "That's not true." Or, "That's not real." She was delusional. It

sounded true. It sounded real, but it wasn't real. Then with my mom, it's her, "I'm fine. I'm doing great. I look good. Don't I look good? I'm fast." So truthfully said, I think that my frustration is that I'm not given enough credibility and I'm not included. I feel like they need to follow up with me separately, like, "Listen to them, ask them questions. But let's find a way to connect offline so that I know that you heard it from my perspective." I think if my dad would've been diagnosed earlier, some of my mom's ongoing health issues would be resolved.

Melissa (33:08):

I insert myself a ton, but it's sending it out there. So if she comes to visit me or I visit her, I always send a message back to her doctor and say, "Here are the four things, or whatever number." And I bullet them out, respecting her time, and I say, "This is what I'm seeing. You need to know this because you're not seeing this. Because you have 10 to 15 minutes with my mom on a visit, and she has all these things going on with her, but you're not seeing this." But let's just say this. So I mentioned my aunt's initial encounter with area hospitals and all the emergency rooms she attended.

Melissa (33:43):

But the first one during her 10-day stay was where I finally felt like I was part of the team. The assigned hospitalist who had just come on for his next long shift, we got really lucky there, so we had one hospitalist at the beginning, which made it much better with me. He addressed my concerns. He huddled. We found times when I would say, "I'll be here today. When are you round?" And he'd tell me his rounding time. Then I would be like, I think he was impressed. He was like, "Okay, let's huddle." And he's like, "God, do you work in healthcare?"

Melissa (34:18):

I knew what words to use, but he's always checking with me. He called me proactively. He even called me and asked me questions like, "What do you think?" There is nothing better. I'm getting goosebumps just thinking about those conversations where he's like, "What do you think we should do? What do you think about the medications?" That's great.

Melissa (34:40):

I would love more people to ask me questions and ask for my opinions and my thoughts. I know that not everybody is as involved as I am, but post discharge now, there's where I felt like I was dumped. So when I was in that experience in that hospital, it was fantastic. But the case worker, the social worker, they all go away the minute the transfer happens to the sniff.

Melissa (35:04):

That was, for me, went from a peak and a high to back to a low, to now I get to start in on DHS and Medicaid benefits, and again, a myriad of paperwork. But the high was being asked, taking time to address my concerns, and looking at me like a part of her care team. That was the best experience I've had.

Jim (35:30):

You're reminding me, a lot of times we talk about patients being in the hospital, and there's often this sense of loss of control. Loss of dignity, but also loss of control.

Melissa d(35:43):

Right.

Jim (35:43):

Being a health system or a physician or hospitalist in this case, when they include the caregivers, when they include the family in some of that decision-making, that also removes it. Now, you're making me think of the family members who feel this loss of control, not just the patient. Like you said,-

Melissa (35:59):

Yeah.

Jim (36:00):

... we are all experiencing it together. When healthcare providers proactively ask, "What do you think?" That doesn't happen enough. I think that's incredible to say, "You know the family member the best. You know this patient. We want your input." Okay, maybe there's a reason why we can't do what you want to do, but we want to be informed by the people that know the patient best.

Melissa (36:18):

She's delusional. So my aunt was completely... She thought she had all of these maladies, and I later was able to analyze why she was telling me she was really sick with all these things. She knew her home was uninhabitable. She didn't want to go back there. So she told them she was blind. She had me bring her a pair of sunglasses, which she wore the whole time. She told me her feet didn't work. She had cancer on her face, her leg, and her arm. She just kept saying these things.

Jim (36:47):

Okay.

Melissa (36:48):

Then she also told them that she was allergic to all these foods, which none of them were true. But guess what? They put them on her charts. So now I've had to tell people, "No, she doesn't have a peanut allergy. No, she isn't allergic to shellfish." But again, that's where we also have challenges. Sometimes it's medications that are doing it.

Jim (37:09):

Sure.

Melissa (37:10):

It's not all dementia, but I will tell you it's more and more prevalent. How are we going to get through that whole what's fact and what's fiction with the patient if we're not doing more discovery work with the family, and hopefully

the family is involved? I know that I'm also talking about an ideal scenario where somebody like myself is vested in the outcomes of that person. That's not always the case. I recognize, my aunt would probably be on the streets today had I not stepped in when I did.

Jim (37:46):

Sure. That's, again, more reason to include the caregivers. That's why the role of caregiver needs to be recognized.

Melissa (37:54):

Yeah.

Jim (37:54):

So Melissa, everything you have shared, I think I'm going to share this episode with my family members because, again, we're in this role right now. This is something extremely valuable. But I want to give you an opportunity to share any last words of advice, any wisdom that you'd like to leave our listeners with. Any parting words for hospital leaders who want to do more for their patients by including caregivers at home?

Melissa (38:17):

Yes. Caregivers are as-

Jim (38:23):

Walk us on the distance.

Melissa (38:23):

Yeah. Wherever they are,-

Jim (38:23):

Yes.

Melissa (38:24):

... wherever they may be, caregivers as a group are coming together. Know that. There have been recent federal and state bills to address the rights and needs of caregivers at the policy level. In April, the president signed an executive order to increase access to high-quality care and supporting caregivers. The order directs health and human services to consider testing a new dementia care initiative that will include support for respite care and provide more support to family members, when caregivers, when a loved one is being discharged from the hospital, get ahead of it.

Don't wait for the policies to be enacted. Differentiate now, and I'll say that again. Treat the patient and caregivers as a unit. Develop a model of care for dementia. I heard that UCLA designed a dementia care program. They tested it. It statistically reduced patient behavioral problems and lowered caregiver distress.

Melissa (39:14):

It's not new news, but I ask myself, "Why hasn't this been widely spread?" We have pathways for cancer. We have pathways for cardiac and other diseases. Why should dementia be any different? Palliative or not, do not discard the needs for therapies and ongoing support. Diagnose and audios is a commonly used term for those of us who have dealt with the disease of FTD. Connect us to community services, including support groups. Look at your data differently. What is the real cost? There are real impacts on healthcare quality, cost, and experience. Look at your codes. Are you looking at the cost based on the individual or their total cost over a period of time? Or even their caregiver? Have they ended up in your hospital? In some cases, caregivers passed before the patient with dementia. That's terrible.

Jim (40:10):

Yeah.

Melissa (40:11):

Identify and evaluate your survey tools. What survey do you need? Do you really improve things? Does it even exist? I know and understand that CMS is the driver for most hospitals, but so is consumer choice. If you weren't talking

to me, you don't know how I feel about your brand, you don't know how I feel about your system. That's critical. Yes, CMS, we need to look at them and think about what's missing in their metrics as it pertains to caregivers. But that's going to take more time. So why not now? And I think we should be looking at home health too. Transitions to home care, especially for dementia patients. Not just upon release from your brick and mortar.

Melissa (40:52):

Where is the next opportunity? And challenge your models. Empower your teams to look at the care they provide through the lens of the caregiver. Incorporate more dementia training, and let us help it design it with you. That's my big one. Don't leave me out of it. Help me help you and be a part of that design. Ask me what you could do better. Ask me where you see opportunities. Tell me your pain points. So that's what I want to say, Jim. I think that's the big opportunity here. We're partners in care for our loved ones. Don't shut us out.

Jim (41:31):

Well said, Melissa. Well said. Thank you so much, and thank you for being on the show today.

Thank you to our listeners who spent time with us today. If you have questions about VIE Healthcare Consulting, a SpendMend company, or if you want to reach out to me or Lisa Miller, you can find us on LinkedIn.

We at VIE and SpendMend love helping hospitals save money and enhance the patient experience. We're hoping, I know for a fact, the episode today gave you some new insights, gave you some new ideas to consider and use in your career and in your own healthcare organization.

Again, Melissa, thank you for being with us today.

Melissa (42:04):

I really, truly appreciate this opportunity, Jim. Thank you.

Jim (42:09):

Thanks for listening to The Healthcare Leadership Experience podcast. We hope you've enjoyed this episode. If you're interested in learning new strategies, best practices, and ideas to utilize in your career and healthcare organization, check out our website at thehealthcareleadershipexperience.com. Oh yeah, don't forget to rate and review us, and be sure to join Lisa and Jim next time on The Healthcare Leadership Experience podcast.

Thanks again for listening.





MEET LISA MILLER

"It's important for hospitals to have a clearly defined cost savings strategy with purchased services as a component to that strategy. We provide our clients with a focused roadmap to achieve those savings through our expertise since 1999."

Lisa Miller launched VIE Healthcare Consulting in 1999 to provide leading-edge financial and operational consulting for hospitals, healthcare institutions, and all providers of patient care.

She has become a recognized leader in healthcare operational performance improvement, and with her team has generated more than \$720 million in

financial improvements for VIE Healthcare's clients.

Lisa is a trusted advisor to hospital leaders on operational strategies within margin improvement, process improvements, technology/ telehealth, the patient experience, and growth opportunities.

Her innovative projects include VIE Healthcare's EXCITE! Program, a performance improvement workshop that captures employee ideas and translates them into profit improvement initiatives, and Patient Journey Mapping®, an effective qualitative approach for visualizing patient experience to achieve clinical, operating, and financial improvements.

Lisa has developed patented technology for healthcare financial improvement within purchased services; in addition to a technology that increases patient satisfaction through frontline insights.

Lisa received a BS degree in Business Administration from Eastern University in Pennsylvania and a Masters in Healthcare Administration from Seton Hall University in New Jersey.

She is a member of the National Honor Society for Healthcare Administration – Upsilon Phi Delta. Her book *The Entrepreneurial Hospital* is being published by Taylor Francis.



MEET JIM CAGLIOSTRO

Jim joined VIE Healthcare Consulting in 2018 and brings to the role over a decade of critical care nursing experience at highly regarded medical facilities across three states.

During that time, he observed both the 'good and bad' of hospital operations in a number of regions, giving him a unique insight and understanding which he brings to VIE Healthcare Consulting's clients.

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MEET MELISSA FISCHER

Melissa is a healthcare consumer experience designer and strategist.

