

# Eldercare Success Podcast

## Episode #50

### Disability and Caregiving: Transcript

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[00:00:00] **Nancy May:** What happens when you have a disability and you're trying to take care of somebody? You might be surprised, welcome to doing it Best with Elder Care Success, where we explore ways to relieve the stress, exhaustion, and overwhelm that we all face in caring for an aging parent, frail spouse or partner.

[00:00:18] Fear, frustration, emotional, and financial strain does not have to be your mo. Stay tuned as we dive into different and new ways of finding more joy together with those that we love and care for. And while keeping our feet solid on the ground, hang tight. There is a better road ahead. Happy New Year everybody.

[00:00:39] This is Nancy May from doing it best with Eldercare success and you know, the new year has always got sort of this bittersweet feeling for me. And besides learning about all the new things that I want to pick up and share with you, there is that sense of, I think, loss that we have in the year that's passed, the year that [00:01:00] we may have lost somebody that we love and a little bit of nervousness and maybe even fear.

[00:01:06] What to anticipate in the new year. Yep. There's lots of excitement as always, but when you're caring for somebody that you love or just caring for somebody in your family, you may not necessarily love them that much, , but there's, there's that sense of anticipation. So, Hopefully the new year coming forward will bring you more joy, a little less stress, some relief, and maybe even some heartfelt memories.

[00:01:34] So this is the first episode or first show for the 2023 New Year. Happy New Year. Hello everybody. This. Is Nancy May from doing it best with Elder Care Success, and this is going to be a rather unique show, one that I've been really looking forward to doing for quite some time, as it's an area that I don't think a lot of us really are aware of. [00:02:00]

[00:02:00] And it's critical when we're taking care of mom, dad, a spouse, or or anybody at that point and what our show is about today. Bias and understanding the bias in the healthcare system for those who have disabilities. Now, a disability, you may be thinking in. The course of our life could be blindness, handicapped, cerebral palsy, whatever the case might be.

[00:02:23] But actually as our parents get older, hearing visual impairments, mobility, anything else that might inhibit their life, their as, as they know it can be also considered a disability in the healthcare system or a comorbidity in some cases. But more importantly, there is an unspoken bias or sometimes even an unaware bias that doctors, nurses, and the entire healthcare system has for patients and individuals who have.

[00:02:55] Type of limitations or disabilities. My guest today is Daniel Hodges, [00:03:00] and Daniel is an amazing gentleman. Oh my God, I'm so excited to have you, Daniel. So, you

can laugh because I'm, I'm just, I'm just thrilled. But Daniel is an attorney by training. He is not a practicing attorney, just so that you know that.

[00:03:15] And what he does is he works with companies and organizations to help them better understand how to. Overcome these, these types of situations that they may not even know or be aware of is going on themselves. Daniel is blind and has been blind pretty much since birth and has been a, I'm not going to say a victim, but a uh, Firsthand experience in some of these issues in our healthcare system.

[00:03:44] He is the founder or co-founder, um, president of an organization, of an organization called Pieces of Me Foundation, and he is the Chief Communications Officer for another company called Pure Access Consultants, which [00:04:00] works with companies on these issues, which we all need to know. So welcome, Daniel. I am so thrilled that you're here with me today.

[00:04:07] **Daniel Hodes JD:** Well, thank you for having me, and I am looking forward to this conversation and just glad to be part of creating some awareness.

[00:04:14] **Nancy May:** Yeah, it's, it's a big awareness and I'm not sure that the rest of us don't even realize that this goes on. We get angry when the healthcare system doesn't work for. I can't imagine how frustrating it is for you and others that you help when there's a sense of, I'm going to say my assumption, maybe it's my bias, that sometimes you may be feeling more marginalized than the rest of us and we are like pissed as heck and can't get what we need.

[00:04:42] Right?

[00:04:44] **Daniel Hodes JD:** Absolutely. And. You know, there is, um, there is a lot of data out there that suggests that if you are perceived as having a disability, then the quality of care goes down. The incidence of comorbidities goes up [00:05:00] and it's. a lot of different factors. Everything from structural inaccessibility within the healthcare sector, but also the, the latent effects, as it were, what we call in the advocacy community, the medical model of disability, which really equates quality of life and.

[00:05:20] Potential for enjoyment, potential of, for contribution with the presence or lack of disabilities in a way that is not supported by the lived experience of the millions of us with disabilities who are out there living life and doing our thing. It's, it's a very arcane. Thought process that just hasn't quite been rooted out yet, largely because it's, it's difficult to get the conversation started in a safe and healthy way where people, including providers don't feel threatened, but where we can also try to attack the underlying assumptions without attacking the people.

[00:05:59] **Nancy May:** [00:06:00] I think that is so well said. And I was reading some research earlier today. What, what happens inside of medical practices when they're addressing these issues or even how doctors are trained, which they're not trained to address them. They're taught that there is an illness, and you fix us, and when you've got a disability or a different way of, of growing up or, and living or even growing into, I, I'm going.

[00:06:30] I'm going to go out on limb and say that doctors may even think of you as broken and you can't fix it. So why even try? You should never assume. But is that correct or am I perceiving that wrong?

[00:06:45] **Daniel Hodges JD:** That is spot on, and the only thing I would add there is. You either get that end of the spectrum where the services effectively are disconnected or you get what you might call [00:07:00] overtreatment, where something that may or may not make medical sense.

[00:07:05] In one instance, maybe the last hope at preserving, let's say a sense or an inability or, you know, something and maybe you, you, you tweak the rules a little out of desperation as opposed to sound decision making. An example would be when I was, when I was just about to turn 16, we had a. One, particularly ambitious ophthalmologist who wanted to try to restore vision in my right eye, which had never seen much.

[00:07:39] And you know, the risk was, well, okay, there's a possible risk you might lose whatever little bit was left. And you know, that's really, you know, the only concern. So why not try it? Well, in reality, there was also the risk. The eye could actually reject the implant despite having the [00:08:00] steroid drops. And that is precisely what happened.

[00:08:03] And so, you know, the loss of that vision in that eye wasn't, I mean, it kind of bites, but it's not the biggest deal in the world. But I'll tell you, having the eye reject, anything is not pleasant, and I use that as an example. And there are other examples too. Two of my, two of my children are survivors of a rare eye cancer called Retinoblastoma and mm-hmm

[00:08:28] So we've been in communication with families all over the country who deal with the same things we had to deal with who aren't quite as fortunate as we are. And sometimes find ourselves in a situation where a surgeon will actually go beyond. What would be a safe threshold for preserving the child's life in order to take a Hail Mary at, at saving the child's eye and maybe any ounce of vision that might be left.

[00:08:58] **Nancy May:** The doctors are kind of trying to play [00:09:00] God. Yeah. In fixing the system as opposed to dealing with the health and wellbeing of the child. Or in our cases when we're dealing with elderly parents, the, the parent, the quality of life.

[00:09:13] **Daniel Hodges JD:** Well, yeah, on that front, you know, and I'll tie you this back to it here in a second.

[00:09:17] In this case, unfortunately, you have instances where the child actually dies cause they tried so hard to save the eye. And yeah, and that's where this comes back with, with elders as well. We need to be really sure that the stigma of disability isn't influencing the, the decision-making process to the point where it might actually.

[00:09:41] A provider to really go outside of the rational box that they would normally be in for making a decision as far as what interventions are warranted.

[00:09:52] **Nancy May:** Yeah. Making things worse. You know, I'll, I'll give you a similar example, although my mom did not. She really did have a [00:10:00] disability though as I, as I look at it, she had dementia and had a massive brain aneurysm, which ultimately killed her.

[00:10:06] Over a period of days, we, we put her into hospice, but when I got the call, when this happened, we knew that something was going off and, and I was ready to fly down from Connecticut down to Florida, where, where she was living, and the doctors called me and said they were going to fly her out to another.

[00:10:25] At 91 and do brain surgery to save her. Now, , I have to say, first of all, it helped that I, I knew my mom's wishes and what she wanted in, in the course of her life if it came to this point, which was she didn't want to be put on life support. She didn't want to suffer. And that made my decision easier. But that the doctors, I was.

[00:10:47] Bluntly put, I was pissed, , that they would even consider going to those kinds of measure measures and ultimately, in my opinion, creating greater pain and suffering for [00:11:00] somebody that that couldn't speak for herself and that I find to be thoughtless, , it's, you know, they're playing doctor and I put playing in quotes or, you know, playing God.

[00:11:12] And the same goes for any adult child who's, or even spouse who's taking care of a frail partner or spouse at the same time, and then trying to figure out, they can't speak for themselves. They've lost their sight. There's, there might be a little, little bit of dementia or. Disillusion or delusion meant that's going on through Alzheimer's or, or Parkinson's or, or some other illness.

[00:11:35] And the ability for the individual to represent themselves, they become almost invisible in the system or on the table or in the bed as a doctor is trying to communicate with others around to figure out what's going on. I'm not sure that's

[00:11:50] **Daniel Hodges JD:** That's right. Definitely. And you know, as we discussed in a, a previous conversation, you know,

[00:11:57] It was quite similar [00:12:00] but a situation of my own. Earlier on in life I was 23 and I had been supporting my dad through his last several years of life where he had been dealing with Agent Orange neuropathy and you know, it was me and my mom who generally. where they are advocating for him calling the ambulance when he needed it.

[00:12:22] In my case, you know, if he fought, if he failed, it was up to me to help him get off the ground if it didn't require an ambulance, right? All that sort of thing. And when the last trip to the hospital came. You know, it was my job to notify the family and to really be that person sitting with my mom and the doctor when they were presenting the options and mom looking at me saying, what do we do?

[00:12:46] And me saying, look, it's, it's time because the interactions with the drugs and, uh, you know, the symptoms from the disease have just gotten to a point. Whatever's gone on in

the last few days, [00:13:00] there's, there's really no coming back from that. So it's time just to let things be, and it's an incredibly difficult decision.

[00:13:08] And it's one where, I mean, again, we've talked about times where maybe the treatment is too aggressive, maybe the treatments aren't aggressive enough. And I think for those listening, It sounds like it's an impossible situation, but really that's not, I don't think it's the point either of us is trying to make more, where we're really trying to say, look, be part of that decision making process.

[00:13:33] Please ask your providers to walk you through their analysis so that you can follow their train of thought, and don't be afraid to trust your intuition. Ask questions even if you feel like you're stupid questions or not. and make sure that you're on the same page and that you're feeling like your voice and the voice of your loved one is being represented.

[00:13:58] That is your rights.

[00:13:59] **Nancy May:** The [00:14:00] doctors and the nurses tend to sort of take over because it's their territory that you're, we are living in at that time. But you're, you're absolutely right. You have to sort of insert yourself and assert yourself at the same time. Now I want to sort of turn this on its head, just a.

[00:14:16] You are, you are blind, and you are taking care of your dad and then ultimately your mom. I'm curious to have the, the discussion really in understanding how as a caregiver yourself, the healthcare system treated the situation that you were overseeing. Did they actually give you the same kind of respect that you think somebody like.

[00:14:37] Who's not blind or doesn't have any physical disabilities or you know, gimme too much coffee. Maybe I do have a mental disability at times, but just ask my husband. But have you seen any impediment or impairment to how that works for you as a caregiver? Because I know a number of people who are out there who have [00:15:00] disabilities and are caring for an aging parent or a.

[00:15:04] and I'm curious to see, you know, what, what is it like to be in your shoes?

[00:15:09] **Daniel Hodges JD:** So, anytime I walk into a clinic with my white cane with someone, there's going to be that assumption that I am the one being taken care of. Not the one advocating you're the problem, right? Yeah, yeah, yeah. So you have that problem.

[00:15:26] You have, you have the, the issue where, you know, paperwork is generally not going to be accessible. You know, the, the signage and Yeah. Facilities is not accessible. And all this, although this doesn't affect me as, as much as it would say a wheelchair user. One of the stats I came across in doing research for my law degree led me to a study that said, despite the fact.

[00:15:54] That the Affordable Care Act requires medical facilities to be accessible. Full [00:16:00] stop. In California, only 13%, and that's one. 3% of facilities were compliance.

[00:16:08] **Nancy May:** These are medical facilities you're talking about, right. Yes.

[00:16:12] **Daniel Hodges JD:** Oh my goodness. Yes. Yeah. Um, so, so this, so there is a major, major problem with literally even getting in the door, let alone trying to have your seat at the table.

[00:16:25] With the kind of persuasion and the kind of respect that, that you are entitled to,

[00:16:31] **Nancy May:** you have better luck getting into the local diner than you do in the, in the local hospital in California, it sounds like.

[00:16:39] **Daniel Hodges JD:** And, that's really sad. I don't have statistics to bear this out to, to prove this.

[00:16:45] But I'll tell you, I have no reason at all to believe that California's an outlier there. From the advocates I talk to, California's this the only one where I found the stats so far. I would just about bet you that it's the same anywhere else in the [00:17:00] country.

[00:17:00] **Nancy May:** I would tend to agree with you and, and that's sort of my gut reaction because I think that most people, well, people who are in severe distress usually arrive at an emergency department first.

[00:17:14] Right? Yep. So they're, they're non ambulatory, meaning they can't walk or, or roll in and they arrive by ambulance or stretcher somehow. And a, and a loved one's not walking them into the hospital. Or if you are and there's a problem, you, you better run in there first and yell, help, I need X, Y, z. Get out here fast because we can't walk in.

[00:17:36] Yep. So, it's, you know, this is, this is actually very distress. For me to, to hear this because we're, we assume that our healthcare system is, is an equal opportunity provider for everybody. And when we think about diversity environments, it's typically male, female, black, white, people of different color. And the, [00:18:00] the disability is an afterthought, which I don't think is intent.

[00:18:04] but it's more or less likely. And again, this is sort of my insertion here, that we just don't know how to have the conversation to begin with, including the doctors. Is that correct?

[00:18:15] **Daniel Hodges JD:** It is. And let me provide a little historical context here, please. The legislation that brought people with disabilities out of facilities, And allowed us to live out into the world is only a couple of generations old that a movement to allow us the right to exist in the community.

[00:18:38] What they started to call, you know, getting us out of the facilities, out of the homes and out of being

[00:18:44] **Nancy May:** institutionalized, basically we're talking about, yeah, we're talking to be politically incorrect, but Correct.

[00:18:50] **Daniel Hodes JD:** Yeah, we're talking, we're talking 1950s, 1960s, and even with that, there is another set of legislation that was locally [00:19:00] based called the, this is their word, called the Ugly Laws Really, which basically said if you were unsightly.

[00:19:06] or you know, the, the, your, your presence could be visually disturbing to someone else. You were required to remain in your home and outta sight, and those didn't all go away. until the 1970s.

[00:19:21] **Nancy May:** Oh my God. Oh, what? Yeah. I mean, what kind of world have we lived in without even being aware of this? It's, ooh, I mean, you have taken my breath away and quite frankly, almost turned my stomach thinking about it.

[00:19:35] It's the only way it can, I mean, visceral viscerally. I, I, not that turn my stomach at you, but that the concept that, that our society has just been so ignorant on, on this whole process. Yet there is, there is a movement, I think, among certain people to try and change that. But it is so slow and so, so difficult and [00:20:00] it shouldn't be because we look at, we are looking at your situation, but we're also looking at anybody who might be.

[00:20:08] In the need of, of helping somebody else and being inhibited to do so, or unable to do so because of a system that doesn't treat them as an equal.

[00:20:21] **Daniel Hodes JD:** Absolutely, and I think that's important to bear in mind because if you are someone who has had full mobility, all fa, all of your site, your faculties, et cetera, For all of your life, and those are starting to wane.

[00:20:35] You've grown up in a world where you weren't taught about those discrepancies, and you're also transitioning into a world that is not built for people with disabilities, right? To be part of society. Structurally and culturally. We're saying, wait a minute. Why are these buildings not accessible? Why are these.

[00:20:59] You know, [00:21:00] biases allowed to exist, and the fact of the matter is, the answer is we collectively have not addressed them and really gone back and revisited the expectation that these discrepancies were based upon. You know, we can say in 2022 that. We expect more for everyone, but the, the medical establishment and most of the rest of the world is not built on the kind of assumptions that we really want to carry forward in that, in that regard,

[00:21:31] **Nancy May:** It's very easy to see how anger builds up in, in us and, and our parents and, and others who are trying to live well in a world that is just not, just not built for.

[00:21:45] For people who have a disability, and geez, you know, even as a physically unpaired caregiver for an aging parent, I saw similar things with, not so that my mom and dad would get angry, but I would be frustrated in trying to [00:22:00] provide the proper care and support just mobility wise in getting around, thinking about.

[00:22:05] Well, geez, you know, how do I get them in and out of a restaurant? Um, is there, is there a way to do so with respect and how will other people behave? When mom gets a

little boisterous is when sh, you know, her dementia would allow her to do. And thankfully down in Florida where, where they were, the restaurants were always upbeat and positive and support.

[00:22:27] Yet I have seen just the opposite in other places around the country. And it, you know, it's, it's frustrating for, for us caregivers who don't have the disability now. I wanna sort of again, sort of do a, another turnaround and talk about some of the things that make things more difficult from an accessibility perspective.

[00:22:47] One, which we talked about the other day, was story of a, of a woman who needed to call an ambulance, and she had been a pH, a physical disability of her entire life, and she was in a wh. [00:23:00] and when the paramedics came, they told her they could not bring her service dog with her in the ambulance. Now she resided alone.

[00:23:07] She needed the help and had no way to then take care of the service animal at her house or, or even. She needed this dog to be with her, so that was frustrating to hear. And I'm, I'm presuming you've probably heard things like that before, but when we can't get the, the materials that we need, how do we go about getting things that can be accessible to somebody who might be blind as a caregiver at a hospital?

[00:23:35] Even if it is on a tablet, it may not have a read. Tool on it. Are there things that you have done to say, help me? And presuming that you don't wanna be in a position to say, help me, I can't do this because you're a talented, intelligent individual and to be at, at the, you know, the need of somebody else when you shouldn't have to be is gotta be frustrating.

[00:23:55] **Daniel Hodges JD:** Absolutely. And I would say, you know, you know, the, the ambulance example [00:24:00] highlights two sides of a problem. One, obviously we. To provide some extra level of training for people, not just at the end of the medical journey, but from the very beginning. Right. And by that same coin, there's no shame in admitting that we could all, almost all of us, I'm speaking for myself here.

[00:24:24] Could use some sharpening with our self-advocacy skills because the world tries to beat it out of us, even as we gain those skills and there's such power and remembering that, you know, we're not the problem. We are living in a system that was designed to meet the needs of one segment of the population and not.

[00:24:48] It's not a failing on our part. It is a design problem and it's a fixable design problem.

[00:24:54] **Nancy May:** Can we speed this up? I mean, can we fix it faster?

[00:24:59] **Daniel Hodges JD:** [00:25:00] Daniel , trust me.

[00:25:00] **Nancy May:** I'm looking to you for help.

[00:25:04] **Daniel Hodges JD:** Well, if my mom and dad could have used it too. believe me, I'm hoping to Anita that and that's why I do the work I do, because I think it is fixable.

[00:25:13] There are so many of our stuff out there doing it and, and I think, you know, you mentioned the tablet for an as an example, and most people don't realize this, but if you get an iPad or an Amazon Kindle or almost any mainstream phone or tablet or computer out of the box, it's going to. Some rudimentary speak to text and some other accessibility software natively built onto that device, if you know where to find

[00:25:44] **Nancy May:** I know Microsoft Word does it and quite frankly, if I'm, if I'm writing something and I'm reading it, what I will do is put the audio reading component on so that I can hear it, close my eyes and listen to it as opposed to reading the words. And it's interesting. [00:26:00]

[00:26:00] **Daniel Hodges JD:** Yep. So with regard to the medical paperwork, for example, Really, the more facilities transition into that, it's going to be more accessible.

[00:26:09] It's also going to be more en, environmentally friendly. It's going to be more cost efficient. So it's an example of really by pushing for. Our seat at the table. We're also solving design problems that are impacting other parts of the healthcare sector as well. And that's the beauty of design and that's why it's so important for us to be very vocal, respectfully vocal for sure, but vocal about our needs.

[00:26:40] not because it is selfish of us, but in all reality because it really drives the conversation and the innovation forward.

[00:26:47] **Nancy May:** Innovation is, is key. There's so much that's going on in the healthcare system that people are driving towards innovation. You know, investment capital, they're, they're running towards the healthcare system because so many are getting [00:27:00] old and decrepit and maybe, maybe not decrepit, but we're getting.

[00:27:05] anyway, when, when you're dealing with a situation like you have over the years, and you know, if not, I'm curious to find out. When you find resistance from a medical professional, a doctor, a nurse, it could be an administrator of just not knowing how to speak with you because some people are afraid of people who are different than.

[00:27:29] and I know that they're dealing with healthcare situations and an illness is, is one thing, but when they're, they need to move on a faster pace. So for example, um, doctor only has 20 minutes on average to deal, do with an exam. You may need to take longer because you have an earring hearing impairment.

[00:27:49] You maybe have a mobility impairment, or excuse me, a parent does. How do. How do you extract or pull out the extra time and attention that [00:28:00] you need when a doctor just doesn't have the ability to do so? Is it scheduling your, your appointments at different end of the days or just insisting and being a, a pushy, pushy patient,

[00:28:12] Or sometimes you got it right?

[00:28:15] **Daniel Hodges JD:** I would say they do say that scheduling earlier in the day has its advantages simply by virtue of the fact that the later in the day, the more likely it is that

the day has gotten off track. Yep. But I also think this is where the relationship really starts to come into play.

[00:28:34] If you are looking at a one-off with a doctor, it's really hard Yeah. To, to thread that needle. But if you can build a rapport, Where you're just putting one brick in that wall after another. Eventually you have, eventually you have your self ability that you can actually deal with. And I think the last part is to do the best that you can to [00:29:00] be prepared so that you're concerned and your questions are, I mean, they don't have to be, as you know, hu as, as tight as humanly possible.

[00:29:11] if they're constructed in a linear way where there's not a lot of fluff, but where, where there's, you know, some strategic thought of, okay, these are the questions I have. Mm-hmm, they're clear, they're concise. That's really going to help tighten the conversation and it's going to help keep things on point.

[00:29:30] Which is really going to help, is really gonna help keep the appointments focused and

[00:29:36] **Nancy May:** powerful. So really, it's like setting up for a business meeting or any kind of professional meeting. It's get your docs in a row, know what the agenda is going to be, look for the best possible outcome, or at least answers to your questions so you know what the next steps are.

[00:29:50] And then, Tell the, the professional, the doctor or or therapist, whoever you might be dealing with, this is what I need to get done. What am I missing? How do we [00:30:00] get it done? And be direct about it and let them know that they are dealing with somebody who can stand on their own two feet or, or not, no pun intended, but, or maybe pun intended, but that they're dealing with somebody who.

[00:30:15] Either a strong advocate for the individual that they're caring for that may have the disability and I may not be able to talk for themselves, especially somebody who might have had a stroke or something like that, but as organized and possible and tight and meet them at a peer level. Yeah,

[00:30:31] **Daniel Hedges JD:** and there are two really effective ways I think one can do that and really set the stage well, because I love your agenda example, right?

[00:30:40] One is you. Walk into the office or enter into the office and maybe have a written list of questions and concerns. The other, and, and I would advise doing this 24 hours in advance if you can, is most providers now have some form of. [00:31:00] Electronic medical record and or, you know, communication platform, whether it's M Chart or one of the other competitors, right, where you can send a message to your provider.

[00:31:09] So why not? If you know what your, if you know what your agenda is, 24 hours in advance, make a note to your provider what that subject line saying. You know, tomorrow's meeting and in the message saying, Hey, here are the things I'm hoping to cover tomorrow so that you can be aware ahead of time and send it.

[00:31:27] and that way either beforehand or during the appointment, they can pull it up and they can actually use that as a checklist. They can run through the questions and comments in their mind and consolidate them the way that they see fit. Then everybody is literally on the same page

[00:31:44] **Nancy May:** and you've got everything documented.

[00:31:45] So if there's any questions, it's in their records and it's in yours as well. And if there's pushback, you can say, Hey, wait a second, page two, item three. Yep. Working like a lawyer, Daniel. Right? Absolutely. So this has really been [00:32:00] great. I'm gonna do a quick sort of summary and please fill in the blanks if I've missed anything.

[00:32:05] And before we end, I also want to just say one more thing is that I have seen people in the emergency room and actually heard about them through my mom and dad's lead aid, Millie, who I just love to. and there sometimes is language as a barrier. Now it is not a physical disability, but it is an impediment to getting quality care.

[00:32:25] If in fact that facility only speaks English or, and you only speak Spanish or, or Chinese or Mandarin or the other way around, where you're in a, in a foreign environment and you're the only one who speaks English and nobody else does, you are going to. So, unless you've got a translator. I had a dear friend of mine who grew up in China and she would volunteer at the hospitals in New York to translate for the Asian and Chinese speaking patients in the emergency room who couldn't get the care that they needed.

[00:32:56] So those, those kinds of individuals are very rare and hard to [00:33:00] find. But Millie at one point was in the emergency room with my. and saw and heard this poor older gentleman on a gurney in the hallway screaming and crying. He was freezing. He was cold, and hospitals are always cold, but nobody was paying attention to him.

[00:33:15] And all he was asking for was a blanket simple, right? Yep. So she was able to. To say, you know, wear the blankets. She understood Spanish and, and helped the, the gentleman, but that shouldn't be the case. So please understand that a disability is not necessarily a physical or a cognitive disability. It could actually be a communication disability, you know, inability to communicate in a system that you just don't have control over.

[00:33:41] So that's, that's critical, especially if we're dealing with parents who. , not even no English or English is the second language. And when they're frightened, it becomes more exacerbated. So when dealing with doctors and you've got a disability, the first thing is communication. Communication, communication.

[00:33:58] That's the first three things. . [00:34:00] Yep. Meet them at the same point that make sure that they understand that you're a peer no matter who you are and, and what the situation, whether you be the patient or the advocate for the patient. Make sure that if there's fear or anger or you're being rushed in any way, you calm the other professional down the doctor and you say, this is what we need to address.

[00:34:20] It's your job as a caregiver to deescalate their anxiety to get what you need. Move quickly so that time can be on your side if need be. And don't be afraid of the consequences. If you are angry yourself or frustrated, just tell the doctor or the, the. I'm frank, frustrated, I'm angry, I'm upset, and here's why.

[00:34:44] And then shut up and let them respond and get your. and then just understand that it's not them all the time, much as we may blame them because they're in the system. The system has unfortunately not been created to help [00:35:00] all of us get the support of your state agencies, your representatives, try and push anything that may be going through in your area or even not even aware of in your area.

[00:35:09] Just let them know. I mean, the statistic that you said that was. 13% of the hospitals in California were not ADA compliant. Correct. Or, or they were only 13% were ADA compliant. Yeah. Yeah. Wow. That's amazing. And, and like I said earlier, you have a better chance of go being wheeled in on a gurney and getting the help that you need, meaning a cup of coffee, in, in a coffee shop, or a deli or a diner, then you probably are in a, in a hospital if you need it.

[00:35:38] are there other things that, that I've missed, Daniel, in this short episode that you can fill in and just tell us how do we, how do we get better support when we're, we're, we've got a disability or we're taking care of mom and dad that has something that's a, a disability that may not be respected?

[00:35:54] **Daniel Hedges JD:** So I know we're running up against time, but I wanna squeeze two more things in.

[00:35:57] Please do. One is [00:36:00] we as advocates, Have the right to find specialists or even primary care providers with whom we feel the right vibe, have the right rapport, and sometimes somebody can be excellent in their field and the skill just isn't transferrable for what you need, and that's okay. So don't be afraid to look for the right fit.

[00:36:27] It's not a personal thing. It's not a Oh, that doctor didn't, you know, whatever. They're good at what they do and if, if that, if that isn't meeting your needs, then it's probably time to reexamine.

[00:36:40] **Nancy May:** It's not personal. Yeah, it's business. Exactly. Exactly. Medical business.

[00:36:44] **Daniel Hedges JD:** Exactly right. Exactly. Your business, and we talked about this offline a few days ago, so much attention goes to what someone may be losing the ability to do.

[00:36:57] if they're in the process of acquiring a [00:37:00] disability, and, and that's to some degree understandable, because we have to adapt. We have to make sure that immediate needs are met. . But the tragic offshoot of that is that many, many times, the remaining abilities, the gifts, the talents that each of us has are often overshadowed in that process.

[00:37:20] Oh yeah. And one. Stat that really crystallizes that point is that there was a study that came out a few years ago that showed that 25% of elders who died by suicide had seen their doctor that day.

[00:37:34] **Nancy May:** Oh, we did talk about this. It scared the daylights outta me. You're absolutely right. and suicide, yeah.

[00:37:39] Among seniors is increasing. We talked about it in the teens and the younger generation, but the suicide in seniors and and older people is not being reported as much. And it's, it's a tragedy. That's a tragedy. It really is. It is.

[00:37:53] **Daniel Hodges JD:** It is. And it's one thing where, again, There's a lot of components leading [00:38:00] into this problem, but one of them that we can do something about today is helping make sure that our seniors have a way of maintaining that quality of life by leveraging, utilizing, and.

[00:38:13] Expanding upon those gifts and talents, even if they're dealing with a chronic illness, even with, if they're losing a sense or losing their mobility, okay, take care of those needs, put the right infrastructure in place. But you know, please do whatever you can to, to not let the gifts, the talents, the interests, the things that bring the zest of life.

[00:38:36] Don't let those drift away in the process cuz there. Adaptive techniques. There are groups, there are many, many resources out there that can help someone maintain that quality of life, and at least that's one less thing that contributes to a potential suicide.

[00:38:53] **Nancy May:** They say that when the, the feeling of pain, be it physical or emotional.

[00:38:59] Is [00:39:00] removed, the thoughts of suicide also leave. Yep. And there's a, I I can, I can understand this. I'll, I'll share, you know, a quick story before we go. There was a, a young man, my lead aid Millie, her, her grandson, who would visit my mom and dad and, oh, he was, he's, he was, he's still is. He's a, he's a great kid and is now a young.

[00:39:21] and he would come to the house and quietly sit with my mom and hold her hand and listen to her and say, Audrey, how are you today? You know, I love you. And give her a kiss and just, just be gentle and kind with her. It was so, it was so wonderful to see. And. Her heart, you could see her heart just explode with, with love and, and care for this kid.

[00:39:45] And when she was dying, her, her mom and her grandmother brought her, brought him in to see my mom as she lay in her bed, just unable to, to hear or see anything. I'm sure she heard everything, but she, she couldn't communicate. And at the end of his [00:40:00] conversation with her, he said, I love you. and just brought tears to my, yeah, just to my, to my eyes does now thinking about it.

[00:40:06] And yes, she has a grandchild, my, my sister's son who is in Oklahoma. But to, to see the, the love that was there was, was very special. So bringing, bringing the older people

together with the younger people who really know how to connect and communicate can bring joy to both sides of the generations. I do encourage it.

[00:40:27] And if, even if it's, even if it's just simple, just sitting there and and smiling and watching.

[00:40:32] **Daniel Hodes JD:** Absolutely. And remember that despite the medical team's best intentions, they're not equipped to fill that void. They're not even equipped to, to bill to, to send you off to the right. Social supports are community resources.

[00:40:50] **Nancy May:** There really isn't. They're all transactionally based. Very much so. Everything is right.

[00:40:53] **Daniel Hodes JD:** Yeah. Yeah, yeah. And, and, and even. They're focused on how do we restore what has been lost or how [00:41:00] do we treat this, or how do we treat that? Which again, is often a deficit model, which is why I brought that stat up and I'll ties together by saying, let's, let's really focus on getting people the support they need so that we're not looking to the medical system to fill all of these gaps because they can't, and to the extent that we're asking it to do more than it.

[00:41:23] Possibly able to do. It's really compromising care. It's diminishing quality of life. It's causing all of these problems. So that's all, all of these various aspects tie

[00:41:33] **Nancy May:** together, celebrate life no matter what your gifts, cuz we do have them. Yep. And every day is a special day, as I say. Right? Yep. Every day counts.

[00:41:41] Even more important. Everyday counts, no matter what your ability, and there is no disability. It's just a different type of ability with. I would say thank you, Daniel. It has been a gift and a pleasure. I am so glad that we have come together and that you are in my life now too as a, as a friend and a colleague and [00:42:00] that I have been able to share you with everybody else here on Elder Care Success.

[00:42:03] So thank you. Thank

[00:42:04] **Daniel Hodes JD:** you for having me. It's been a great conversation.

[00:42:06] **Nancy May:** Take care, Daniel. We'll see you all soon or we'll hear you soon. It's Nancy May at doing it best with Elder Care Success. And if you like this show, I can't think of a better gift to give anybody than a link to the show. It's really easy and it doesn't cost a dime, and it's the best ability you can do to give as a gift.

[00:42:24] We'll see you soon. It's Nancy. Bye-bye. This show is sponsored by Karen Mani, the publishers of How to Survive 9 1 1 Medical Emergency. A step by step guide before, during, and after. For your own personalized free file of life, go to [www.howtosurvivenineoneone.com](http://www.howtosurvivenineoneone.com). All trademarks, brands and comments are not intended.

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