

## LNP 294 Wheelchairs for Catastrophically Injured Patients Steve Henry

Pat:

Welcome to Legal Nurse Podcast. This is Pat Iyer with Steve Henry, talking about a subject that influences catastrophically injured people and has a direct impact on the work of life care planners and legal nurse consultants.

Steve has vast experience in home care, durable medical equipment, adaptive feeding, and complex rehab technology. That technology seems to be changing and improving all the time. He focuses on mobility-related injury prevention with catastrophic cases.

Steve, welcome to the show. I'm so pleased you had a chance to be with us today.

**Steve:** Thank you, Pat, for having me. It is a real pleasure to get to speak to

your audience.

**Pat:** Tell the people who are listening about your qualifications regarding

long term mobility use.

**Steve:** Well, as you mentioned in the opener, I have extensive experience in

just about every post-acute care setting that there is. I've worked in home health, taking hundreds of clients out of various hospitals from Las Vegas to Southern California. I've worked with respiratory. I've worked with wound care, infusion, pretty much everything. Durable medical equipment is the largest extent of my history, and then for the past 12 years I've focused on mobility. And that is, as you mentioned, I'm an ATP and an SMS which is a fancy word for a wheelchair guy, but I also work with adaptive automotive, which is transport of people with adaptive needs, whether that be adaptive driving, controls, or wheelchair accessible vans, and everything related to that.

**Pat:** Tell us what ATP stands for?

**Steve:** ATP is "Assistive Technology Practitioner." It is a certification that

RESNA, the Rehab Engineering Society of North America, worked on with CMS to help validate the qualifications of people who provide

complex rehab equipment. The payers are saying: "We spend a lot of money on this equipment. It's very expensive. It interfaces directly with the clients, and we want to ensure that the people who are providing this equipment are certified, qualified, and knowledgeable."

Pat:

And we have listeners in other parts of the world. We've got listeners at this point in about 52 countries. Tell us for our listeners who are not U.S.-based what CMS stands for.

**Steve:** 

The Centers for Medicare & Medicaid Services. It's our overarching government agency that pretty much sets the rules for the U.S. healthcare system as far as the provision of health care, whether that be hospital-based care or post-acute care.

Pat:

And then you used another abbreviation, SMS. What does that stand for?

**Steve:** 

I apologize, SMS is another certification and a further extension of the ATP. SMS stands for "Seating and Mobility Specialist." It is a certification in and of itself. It's more or less a master's degree in the provision of wheelchairs and seating. Assistive technology covers a vast array of things from augmentative communications, interfacing computers, anything that is adaptive. It could be a mobility device.

So, the ATP is a generalized certification that says you're qualified to discuss assistive technology with a client. As with nursing and any other profession, ATPs may decide to focus on pediatrics, for instance, or they may focus on adults. They may focus on augmentative communications or other home modifications. So, the SMS is just really a drill down on seating and mobility. It's not just a general ATP certification. It's an extension of that.

Pat:

And you know, Steve, when I think about wheelchairs, and I put this in the context of an international audience, I had an experience in 1972 in India when I went to visit my husband's family for the first time. We got off the plane. We walked through the parking lot, and there was a beggar who was dragging himself by his elbows with his hand out, and his legs were paralyzed.

And in that instance, I thought, "I'm a nurse. I always assumed that people who are paralyzed had wheelchairs." And that confrontation in the parking lot

with this beggar made me realize that for some parts of the world it's a luxury to have a simple wheelchair, much less the ones that you're describing which are much more elaborate and can be electronic.

I just want our listeners to think when we are talking about wheelchairs, we're not talking about the wheelchairs that—and correct me if I'm wrong—are in hospitals in which people are pushing people from department to department. We're talking about something that's much more fitted and unique for the needs of the person who's never going to be able to walk out of that wheelchair.

**Steve:** 

You're exactly right. Americans and Europeans for the most part are really blessed that we have advanced beyond what we see in some of the South American nations and some of the poorer nations, the Third World countries. I have clients who will save up their money, and they will fly to Las Vegas or they'll fly to meet me in Southern California with their family. And they'll spend two weeks just to get what they need because they say, "Oh Steve don't, don't, don't. You can't ship it to me. I'll never get it. You know customs is corrupt. You know it's too valuable here."

There are countries where there are no wheelchair providers at all, and so those who don't have the means to go to Europe or come to the U.S., they just do without. There are many organizations that are designed to bring all kinds of donated wheelchairs. And they set up seating clinics, and they'll go down there for two or three weeks, and FedEx or UPS will contribute the shipping containers.

And so, we try to help these people as much as possible, but we certainly are blessed here in the U.S. The wheelchairs we're referring to are exactly what you described, fitted orthotics essentially as closely matched to the body and the level of function that the client has so that they can be as independent as possible.

Pat:

For those people who come to you to be fitted and are concerned about the corruption, how do they get that wheelchair back into their country after you've created it for them?

Steve: They fly it on the plane. That's the only way. Honestly, that's the only way. I mean, I've had clients from Brazil and all over South America.

They even offer to fly me there. If they say, "Fit my wheelchair" and then when it comes in, because they can't wait the month or two it may take to get it developed, they will fly me down there with their wheelchair on the plane to make sure that they got it. It's pretty interesting.

**Pat:** So, then it becomes checked luggage, I assume.

**Steve:** Exactly.

**Pat:** Interesting.

**Steve:** They figured out a way to beat the system.

**Pat:** Wow. All right, so let's think about when somebody has a need for the type of equipment that you supply, how do they find a person with

your background to assist them?

**Steve:** When we're talking about the catastrophic cases, they're primarily

managed in larger rehabs, national rehabs like the Craig Hospital, Rancho Los Amigos, TIRR in Houston. They're all over, RIC in Chicago. So, those are very developed rehabs. They're very comprehensive rehabs, and so they start preparing that client from the date of admission to have all the necessary equipment they need to go home. And they only work with qualified and certified ATPs to

provide this equipment.

Many of the manufacturers won't allow someone who is not certified to even order this equipment because they understand the gravity around this. You must know what you're doing because clients can be injured when someone who doesn't know what they're doing provides something

that's really complex.

Pat: Tell us about those kinds of injuries. I wasn't aware that people could

be injured. In what ways can they be affected?

**Steve:** Many injuries are just caused by benign neglect. You know a client

goes to rehab, the equipment is fitted and at that time, the client leaves the hospital with what best fills their needs at that moment. But as we see, people progress, and they regain function and various levels of abilities over the next several months to a year, year-and-a-half, and

their needs change. Some people progress, and some people decline. If you don't see that client within three to six months after discharge and make sure that they are not already regressing or moving in a negative way with a bad posture, that's going to lead to a posture deviation that we can't fix in two years.

People can be injured by having the wrong seating on the chair, having the wrong backrest, having the wrong cushion. They can be injured by manipulating or propelling the wheelchair in a manner that's not best for their shoulders and their hands. They can be injured by transferring because someone maybe didn't assess a transfer that needed some adjusting in their home or to a vehicle. They try to do more than they should, and they end up falling in the parking lot between the car and the chair or any number of things.

Power chair users who need to manipulate ramps up or down, try to get into a vehicle for the first time in close quarters and they haven't developed those really finite driving skills yet, they can fall off the side of the ramp. They can smash their foot in the door and cause real damage, so certain injuries can occur. The ones that I try to address primarily are the chronic, needless injuries like the shoulder injuries and the pressure sores, pressure injuries.

Pat: I can think of a couple of cases that I worked on in which the attendants did not strap the wheelchair down inside the vehicle and then they were either in a car accident, or they went around a sharp curve, and the centrifugal force pushed the person out of the wheelchair and resulted in injuries. Now I know that's not a wheelchair issue as much as it is a transportation issue.

**Steve:** It can be a wheelchair issue because if you do not consider the wheelchair in the larger context of that person's life and all the environments they have to encounter and operate in, then you can send a wheelchair that is not designed to be properly strapped down. It's not been crash-tested in a vehicle, and so you do have understand what all is involved.

It's more than just a wheelchair to get from point A to point B. Like I mentioned earlier, it's an orthotic and it's almost an orthotic for life. This chair is with them everywhere they go. They can't get rid of it. In the

bathroom, in the vehicle, at the doctor's office, at the local grocery store, at the baseball game with the family, these chairs have to operate in all these different environments.

There are resources out there to ensure that you're getting a product that is designed and tested for what it's going to be used for. RESNA, the Rehab Engineering Society of North America, has developed standards and practices and qualities that wheelchairs must have in order to be useful in a vehicle and be safe in a vehicle. NMEDA, the National Mobility Equipment Dealers Association, they govern all of the adaptive equipment manufacturers and the tie-down securement products that they make. That's the NMEDA.com and RESNA.org. Those are two great organizations anyone can go to and find volumes and volumes of testings and standards and the things that they should be looking for that their client should have.

Pat:

A couple of thoughts have come up to me. I was in Johns Hopkins maybe a month ago with my husband going to the parking lot and I saw a person, a woman, operating a power wheelchair. And this wheelchair was coated with dust and dirt. It looked like the seat was worn away. The armrests were shabby and my general impression looking at her was that this was a person who was very poor, who was not able to maintain or replace this wheelchair.

What kind of routine maintenance or plan to change wheelchairs should be in effect to prevent something obviously essential for this woman's mobility but at risk for breaking down?

Steve:

That gets to the heart of a large problem we have. The U.S. healthcare system is based on reactive, not proactive measures. We have an injury, and then we can treat you. But as far as being proactive, not many of our healthcare entities consider this. For that person you're discussing, she probably doesn't have a maintenance plan. No one is looking out for her.

They will come when she calls and says, "Hey, my power chair is not working. It's broken," but by then a lot more damage could've been done to the power chair or her. It's my goal to try to enforce or institute a mandatory new standard of practice where when you're issued a

wheelchair, and you're a permanent wheelchair user, you have to be followed.

You have to be seen. It's going to be an individualized kind of program where not two people are the same, so some may require a little more attention than others. It may be an annual evaluation and follow-up for some, but for others who are more complex or have certain issues we might see them semi-annually because we understand the cost of prevention is so much less than the cost to treat or fix something once it's broken. That's the human being and the equipment both.

Pat:

Let's talk about the broken human being. I always think of pressure sores when I think about somebody who is paralyzed and the increased risk that they're in. Have we solved that problem?

**Steve:** 

Unfortunately no, not even close. We have the technology to prevent them. We have the technology to heal them. But that little gap of prevention where we see the client and we ensure the product they were issued is still the right product two years later or a year later or three years later if they're using it correctly, that component is still missing.

Shoulder injuries are a problem for someone who must have a manual wheelchair because they don't have an accessible van. They can't afford an accessible van, so the only way they can go anywhere with the family is to use a manual wheelchair that can be folded and put in the car. That person needs to be reevaluated early and often because those are the ones who we see needless shoulder injuries for, numerous falls, and this adds to the cost of their care, and it hurts us all ultimately. Without a proactive evaluation program for each client, we're not going to see a change with pressure injuries or other injuries that are prevalent with wheelchair users.

Pat:

What do you do if somebody gains a lot of weight, as I see happen? I'm thinking of one specific person I know who is in a wheelchair and has been in a wheelchair for 20 years, and he's large. How does that impact the fitting of a wheelchair or the maintenance of a wheelchair or its operation?

Steve:

This client, if he was being seen annually, this problem could be mitigated possibly if the physician intervenes, and they get him on a program to deal with the issue. If it's not a medical issue that they can control, dependent edema or things of that nature, lymphedema, you have to reevaluate the client's need for the device because a user who is overly large or heavy changes the balance dynamic of a wheelchair. For those who have large legs, for instance, those wheelchairs become forward tipping, and you have to be careful with transfers with going down a ramp, with going down an incline in the driveway, because these chairs will tip forward.

The same thing with weight loss. Someone who had a tremendous weight loss or maybe had an amputation that they didn't previously have, you need to reassess them and fit them for the proper equipment. Otherwise, their interfacing with the wheelchair can cause even more needless damage and injury.

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Pat: I'm also thinking about a relative of mine who has severe cerebral palsy. He can't speak. He can't control his extremities, and he's developed progressive contractures of his arms and legs. He's in a wheelchair, and another aspect of this care is that he's at home. His father is now in his late 60s and is responsible for picking up his son

and putting him in the wheelchair. And his father has gotten shoulder

injuries himself from the constant stress of transferring his son from the bed to the shower chair to the wheelchair.

How do all those factors come into play when you talk about contractures and transfer issues when it comes to designing a wheelchair?

Steve:

Unfortunately, some of those, like those with CP, athetoid CP, they do have ongoing changes in their body that neither the wheelchair nor the orthotics doctor can fix. We just manage them the best we can. These clients often need custom-fitted equipment, which is such a struggle because they change so rapidly that the payer sources resist because they say, "We just bought this guy a new custom backrest or custom cushion two years ago. This stuff is supposed to last five years," and so they really are frustrated. They don't want to pay for a new thing, but if the team, the physician, the ATP, the therapist, if they would do their due diligence, they can write up a justification which points to the need for a new wheelchair and what's going to happen if this isn't provided.

It's a hard and lengthy battle, and it depends on the payor source, of course, but even with the best payor sources, it's a hard, lengthy battle. It's a lot of administrative burden, a lot of evidence that you provide to the payers, but you can get it done.

By the time it's authorized, you may need another change, so be careful with that. But, yeah, that's just a constant challenge and then the caregivers are rarely ever taken into account when you're talking about the equipment. The person qualifies for the equipment based on their needs, their diagnosis. It's diagnosis driven most of the time and the caregiver is not taken into account, very seldom.

Some Medicaid programs would take into consideration community activities and mom having to pick up this child, and so they'll go the extra mile and help with adaptive equipment that is not normally covered. There are organizations like Easter Seals and others who have programs that will help these families get equipment that is above and beyond what Medicare and Medicaid would typically pay for.

Pat:

From a caregiver perspective what we're touching on is something that is in the shadows and there's a lot of overlooking of the needs of the caregivers. The caregiver burnout, the repetitive motions, the lifting and the pulling, and you know the way that this type of catastrophic injury affects the whole family is often not part of our thinking.

It may be considered, but in a life care plan itself (and we're talking partially to life care planners today and partially to legal nurse consultants) that the respite care is a consideration for families who are involved in those daily grinding repetitive over-and-over needs of things that have to be done to prevent contractures, to prevent pressure sores. It's a real challenge and I'm sure you see this all the time when you're interacting with families.

Steve:

Yes, that's certainly true. As I mentioned earlier, the caregivers are not considered in this conversation, but for those catastrophic cases and for something where a life care planner might be involved. . . they have alternate pay sources and they're asked to consider what this client is going to need to maintain the best health over the longest period. Certainly in these instances a life care planner or a case manager for catastrophic cases should be considering, and I think they most often do, but when you just look at their response: "We're only going to pay for what this patient needs based on the norm for this diagnosis. We don't see the need for a wheelchair accessible van. They can do an assistive transfer."

They can do that assistive transfer today but what about 18 months from now?

What if a certain caregiver is not as good at making this transfer, this assistance manuever? What about the risk of injuring a caregiver who's maybe a paid caregiver and not a family member or injuring a family member who is now married to this situation with their own situation for the rest of their life? Is it worth arguing over a few dollars to make sure the caregiver is protected from injury?

Let's mitigate that circumstance completely. Let's give them a wheelchair accessible vehicle so we reduce the transfers, which are daily almost, and we reduce the risk for injury to other parties.

So, it is really challenging because the traditional payors, your Medicares and Medicaids, they just don't look at this. So any life care planner or case manager out there who listens to this, I implore you to please consider the caregiver needs in this because if the caregiver is not available or the caregiver is less than what we would like because you have to bring someone in, and they're not that invested in this client, your client is going to suffer and ultimately the case is going to suffer.

Pat:

I think you touched on some important points to think about in terms of a life care plan. I'll summarize some and I'm sure I'm going to miss some, but I think you've emphasized the need to not have an evaluation every five years, to have more frequent evaluations of the wheelchair and how it's fitting the needs of the person, to take into consideration weight gain or weight loss or contractures and how that changes the needs of the client—in this case, the client being the catastrophically injured patient.

You have mentioned having wheelchairs that are safe to use inside wheelchair accessible vans. We haven't even touched on the subject of the person who's capable of driving and maybe the needs of the car might be appropriate at one point in their recovery, but does that change as well and needs to be reevaluated?

**Steve:** 

Of course, absolutely. Peoples' abilities change over time. We're all aging whether we have a disability and age with a disability, or we have a progressive disability, or we're "able bodies." We're all changing. Imagine if your doctor said, "I can't give you a new pair of glasses because it hasn't been five years yet, so just get by." You know you need to drive to work every day, and your vision is compromised.

You can think of many examples of this in life, so yes, the adaptive driving evaluations in my opinion based on the annual evaluations you're going to get flagged for things. This could include, "This client is no longer able to make that transfer safely, so we need to transition from this modified vehicle with hand controls to maybe an accessible vehicle so that we reduce the risk of injuries."

The cost of a van compared to the cost of a hospitalization and a wound and several months of rehab is a drop in the bucket. I think sometimes

people look at the cost of something and they go, "Well, that's an awful lot of money," but they just don't consider what's the cost of not doing it. Often it's much more expensive.

Pat:

I think that came out when we started talking about the Never Events in the United States probably about a decade ago, putting in the perspective of what does it cost to prevent a pressure sore versus what it costs to treat it. We talk about a number of other types of injuries like air embolism and falls and kidnapping of infants from hospitals, all of which happen in the United States.

If we focus on the prevention piece that you're emphasizing, it's very clear that that's a small investment compared to the weeks and sometimes months that it takes to treat pressure sores, especially in this population of people who cannot be off of their sacral area or their heels to try to protect them. What does it mean to prevent that injury versus treat it in terms of dollars? That's a great point that you've made.

Steve:

Thank you. I have a quasi-documentary of my clients speaking in their own words about the trauma to their lives and the cost to their families or to their insurances of their history of wounds. And it's just astounding the stories that some of these people can tell you.

And you know the tragedy is some of them told me, "Steve, when I was in rehab, they told me, 'Well, you're a spinal cord injury and this just goes with the territory. You're just going to have to live with it," and that breaks my heart. You know that's certainly not true. It's not a true statement, and to have that kind of attitude and defeatism is not something we should encounter in health care, especially in this day.

I'm not sure what it's going to take to get people to realize that yeah, one wheelchair and seating system may cost a little bit more than we're traditionally used to paying, but if we go out 18 months or two years and we find that the client is still healthy, and they still look good, and they're still functional, maybe it's money well spent.

Because you can take that and contrast it against a client for whom you did provide the old-fashioned way and you see, "Okay, well, yeah this guy is going in for injections into his spine for unretractable pain. You know

both of his shoulders are gone. He's on medications." And just add up the bill of the cost of monthly pain medications and going to physical therapy and going to a doctor for pain. A few hundred dollars or a few thousand dollars difference in a wheelchair is a drop in the bucket compared to the long-term effect of that slow drip of money going out.

Pat: You've made some great points today, Steve. How can our listeners

find out more about you and the services that you offer?

Steve: I'm on LinkedIn. I'm not big on social media, that's not my generation. So, my company is Design Mobility Specialist and I'm based in Las Vegas and I cover Las Vegas, Southern Utah, Northern

Arizona and all Southern California. And, you can reach me at <a href="mailto:Steve@designmobility.com">Steve@designmobility.com</a> or my cell phone number is (702)

580-1445.

**Pat:** Can you give us your time zone so that you don't get a call at 3

o'clock in the morning?

**Steve:** I'm in the Pacific, but I have clients from New Jersey all the way to

this border, so I'm not unused to having calls placed throughout the

day and night.

**Pat:** All right, wonderful. Well, thank you so much for being on this

podcast and we really enjoyed listening to you.

**Steve:** I appreciate the opportunity, Pat.

**Pat:** And for our listeners, please be sure to tune in next week. We'll have

a new interview. We enjoy getting your questions about our shows or

suggestions for topics. You can reach me at

patiyer@legalnursebusiness.com.

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