

# Adaptations

## Mobility Devices, Driving, and Home Modifications

You can view this presentation at: [youtu.be/QRldia9zdYg](https://youtu.be/QRldia9zdYg)

[00:00:00] **Roberta Pesce:** For our next talk on mobility and devices, driving and home modifications, I will be joined by Sandy Hanebrink, executive director of Touch the Future, a nonprofit organization whose mission it is to create a technologically connected world that is healthy, accessible, and inclusive, providing equal opportunities and maximum independence for all. Hi, Sandy. Welcome, and good seeing you.

[00:00:28] **Sandy Hanebrink:** Hi, everybody. Good seeing you!

[00:00:32] **Roberta Pesce:** Yeah.

[00:00:33] **Sandy Hanebrink:** Alright. I'm excited to be here and to share a little bit of my exciting news. I'm going to start off with a little thing that happened earlier this week on Monday. I was at the UN M Enabling Summit and opened up the United Nations Global Technology Summit with my exciting news of getting an exoskeleton.

[00:01:04] "And technology has genuinely been probably the biggest transformation I've had in my life as a person who's been paralyzed for over 34 years."

[00:01:19] "And thanks to innovative technologies that are available, I'm now able, hopefully the technology gods are with us, come on."

[00:01:45] **Exoskeleton's Voice Recording:** "Press to stand. Standing up."

[00:02:10] **Sandy Hanebrink:** "To stand. And with the push of a button."

[00:02:13] "Left. Right. Left. Right. Left. Right."

[00:02:13] So that's a little bit of a clip of my excitement and how technology is driving innovation. It's pretty special. That was the seventh time I'd actually used the exoskeleton. So, I was thrilled that the technology gods were with us, and everything worked out. Today I wanted to kind of go over quickly some different technologies and information and resources for everyone, as you experience the changes in your life with

rare neuroimmune disorders. Everything from just some slight gait changes with drop foot to, you know, complete paralysis inhibits the way people drive. And so one of the things, the best way is to find a driver rehabilitation specialist. And these resources also have, some of them have links globally. So not just for our US but certainly there are a lot more US options available. And so, the Association for Driver Rehabilitation Specialist directory is there where you can actually go in and see and put in your location, your country and state and just see what's available to you and who's available to you to be able to find that resource. So certainly, a great resource for everyone to be able to see. Did I lose you guys with seeing my screen? Hopefully we're on the same screen here now.

[00:04:19] So again, there's information there. There's other public resources. There's information on home modification resources that are available as well. A lot of times under the government agencies in the US elder care or services for seniors, it's usually seniors and people with disabilities is the way the federal funding trickles down to your local, state, and local governments. So those databases under [eldercare.acl.gov](http://eldercare.acl.gov) will bring you up a database of resources and different recommendations for home modifications and things like that. The Stander Company, [stander.com](http://stander.com), S-T-A-N-D-E-R, also has resources and links for bed rails and couch canes and bed risers, chair risers and things like that that can help.

[00:05:23] A lot of mobility information now has gone mainstream. So, there's portable ramps, there's modular ramps, stair lifts, platform lifts, home elevators, and then this far device here, on the right that looks just like a square with holes in it are access tracks, are portable mats that can be put down semi permanently or that you can take with you to be able to access grass and sand and dirt areas, and things like that. They can be rented, or you can purchase them, they're pretty inexpensive. There's a number of different braces that help people.

[00:06:14] The Saebo brace is one that helps with drop foot. You know, your regular AFOs, which is an ankle-foot orthosis. There's external ones, like an external drop foot one that fits over the shoe. You have your knee-ankle-foot orthosis. And then there's dynamic ones that have, you can adjust the angles and also have some flex and spring to assist. And these, you can get with the help, support of your, typically your physical therapist and your orthotic and prosthetic companies in your areas. Hanger Clinic is just one that is known nationally. But there's usually also local vendors as well. Some can be ordered now, even through Amazon.

[00:07:08] So with mobility, there's a number of different things to consider depending on your gait. So, with walkers, you can go with a standard walker, a rolling walker that just has the two front wheels, the rollator which has a seat and four wheels with brakes, but that one you need to be really careful with so that it doesn't get away from you. And that you're not pushing it too far out in front. There's also upright walkers that give you a lot more, make you stand up a little straighter as you walk and not be hunched over and that. They come in rollator versions as well.

[00:07:52] As you can see the one pictured here with the gentleman that's standing, holding on with like his forearms and then you can see it has a sling seat and then handles in which you can sit down and use to help get up. This one also has a braking feature. They also make rollators with wheels that will go on the beach. So those are really made for the beach and not for every day, they're too bulky and the tires will get a hole quite easily if you try to use it in that manner. So, you've got the scooter. This looks like a knee scooter that's now got a seat on it. I've seen a lot of people who are using this that have leg movement but not a lot of strength for standing or endurance. So, they use these and get around propelling it with their feet. And so, we're starting to see more and more folks enjoying this because they don't have to worry about falling and their energy goes better.

[00:09:00] And then the one with the girl in the striped shirt is a gait trainer or a rear walker. And some people do better with that style walker. They do make those in adult as well. Mobility crutches, you can go everything from your traditional crutches to more ergonomic ones to your forearm or lofstrand. They do come in foldable types so it's easier to you know, store away once you get to the table or to pack. They also come in different weights and materials. So, your carbon fiber tends to be a lot lighter than your aluminum. And they come in everything from custom-sized and made to you to whatever. But what you're seeing more and more now is suspension and different types of stoppers and flexibility of it so that you have more stability, especially on wet surfaces.

[00:10:13] So, when we're looking at wheel mobility, with wheelchairs, you can go everywhere from a transport chair which is going to be your lightest chair, definitely like not custom but it has four casters, the back will fold down, and it'll fold up. And for people who just need that temporary assistance of a wheelchair those tend to work well. You've got folding chairs, custom power chairs, aluminum, titanium. You've got your sit and ride type captain seat power chairs. You've got the one here with the, next to the red one is the Whill, which is actually a portable power chair. It will come into three parts so that you can get it into a vehicle. And it's kind of sleek looking and has a pretty good motors and stuff to climb.

[00:11:26] Then you've got your easy models that fold up as well. There's also scooters that would do the same. With your power chairs, they come with a lot of features, especially your more advanced power chairs. So, you have everything from seat elevators that will tilt forward so that you can reach things better to tilt in space, recline, and standing. Power assist is one of the exciting things to see, so many more options popping into the market. I personally use the smart drive and it comes with a smart watch to activate it. But it also has a wired cable that you can plug in as a backup or some people just prefer to use it by pushing a button versus coordinating with tapping a Bluetooth switch. There's another one that Invacare puts out just below the SmartDrive.

[00:12:27] You've got your e-motion wheels. Quickie has a system. You've got several different add-on devices that make it not just a power assist with a pushing assist type motion but also turns it, you can add in like the ZX to make it with a joystick added to drive a manual chair like a power chair. So, it gives a little bit more options there. Then some recreational units, a couple different ones that you can add on like the Firefly and that which kind of turns your chair into an electric bicycle. There's tons of sports equipment out there.

[00:13:12] Everything from racing chairs and add-on hand cycles like the Cyclone are upright handcycles or the more recumbent style like you see in handcycling races, action track chair, and there's some other companies that make one similar that's like a tank tread, different types of beach wheelchairs including power beach wheelchairs, some of the parks and recreation divisions offer these. So, I know like when I was out in San Diego, I was able to borrow, for free, a power beach wheelchair to get out on the beach up near Pacific Beach. And they locked my manual chair up so that I was able to not worry about that and get sand and stuff in my casters and cushion and that, and really truly enjoy the beach independently, to your racing wheelchairs.

[00:14:10] Alinker, another one the race runners, we're seeing more and more people starting to use that have lower extremity movement but not the balance or the endurance. So, this allows people to get out and propel and actually run utilizing these devices. So, the mobility and walking technologies, the PhoeniX is what you saw me wearing. Indego is another one that's available. That one's out of Vanderbilt University, I know Shepherd Center did some research with that. The first that got FDA approval was ReWalk. ReWalk actually after, as of October of last year has a Medicare code so that has funding. I believe PhoeniX should have their code, Medicare code hopefully by the end of the year.

[00:15:07] Then you have Ottobock has the C-Brace and the E-MAG. They're not exoskeletons, they're considered passive systems. The other three you either have a Bluetooth switch or a mechanism where you can weight shift and then they move you because these are typically used by people who don't have movement. The E-MAG and C-Brace are active stance systems where if you have movement then they can assist through. So, the E-MAG is just an active stance lock and unlock like a typical KFO, but it has an electronic lock and unlock feature so that you can actually bend the knee and have some swing-through gait.

[00:15:57] The C-Brace, you start the motion, and it assists you through so that it helps with your speed and endurance. And then you have the purple one here is Bioness, and that one is electric stimulation type device. So, to help with these type devices, the ones that I just showed you are all the ones that have FDA approval and can be issued to you to use at home. There are some other exoskeletons that you can use in the clinic like Exos and REX and HAL. HAL is the start of the new and emerging technology which is brainwave type technologies that are emerging.

[00:16:47] My organization has started a program called Walk2Walk.org, and we are building kind of a global community that walks so individuals with paralysis can walk again. And so, we do live and virtual events. Individuals can set up their own event. You can do teams, donations, sell shirts and all that, whatever we can do to create the awareness and advocacy around this to get them covered by insurance but also to help individuals be able to get it until that happens and then to assist them with co-pays and repairs and maintenance ongoing. I kind of threw a bunch out there because I wanted just to throw some ideas. I lost you guys, hold on.

[00:17:34] **Roberta Pesce:** No, no, you're here.

[00:17:36] **Sandy Hanebrink:** Alright. I'm back. So, I just wanted to show some of the technologies that are there so I can answer questions and link you to the stuff that you're looking for. Are these new devices to you? Are there other strategies you're looking for? Have you tried these and they're not working? How can we best connect you to the technologies?

[00:18:05] **Roberta Pesce:** Yep. That's, indeed. And thank you, Sandy, for this talk. This was great and thank you for showing some of the videos. I think it's so nice to see it in real time.

[00:18:18] **Sandy Hanebrink:** It's actually right here next to me.

[00:18:21] **Roberta Pesce:** Wow. That's amazing.

[00:18:23] **Sandy Hanebrink:** So, I'll turn it, I don't know, so you can see without getting motion sick.

[00:18:26] **Roberta Pesce:** Yeah, yeah, we can see it.

[00:18:27] **Sandy Hanebrink:** But they're actually approved, and I couldn't get someone to come standby because standing still is my hardest thing and we're having severe storms in the area, so I couldn't convince anyone to come out and spot me to stand for you guys today. And like I said, I've only had it 2 weeks.

[00:18:48] **Roberta Pesce:** Right.

[00:18:48] **Sandy Hanebrink:** So, my first event was going on a hiking trail to see a waterfall. And then my second was opening the United Nations event on Monday.

[00:19:02] **Roberta Pesce:** Wow.

[00:19:02] **Sandy Hanebrink:** So, if you're going to do it, go for the gusto.

[00:19:04] **Roberta Pesce:** Of course.

[00:19:05] **Sandy Hanebrink:** But I really wanted to be able to answer any questions that the people out there had.

[00:19:09] **Roberta Pesce:** Yeah, I'm trying to see. I had one that popped up, I think this one you can definitely answer, "Who should you work with to get this equipment?"

[00:19:19] **Sandy Hanebrink:** The exoskeleton or any of it? So typically, all these you would be working with your occupational therapist and physical therapist and/or your physiatrist. Even your local doctors. If you've got questions on the exoskeleton, certainly reach out to me and we're working pretty closely with all of them, right now, to try to get the word out and help with getting reimbursement coverage and that advocacy. But more importantly doing events to help pay for them so that people can get them now and not 10 years from now.

[00:19:57] **Roberta Pesce:** Right, yep. And I know you touched on this briefly, is there any financial assistance for equipment?

[00:20:08] **Sandy Hanebrink:** Depending on the equipment. So your braces, some of the exoskeletons depending on your insurance, some of the Medicaid waiver programs and then walkers and things like that are covered, the recreational equipment, the Challenged Athletes Fund, there's some other grantees out there that have gotten, Chris Reeve Foundation, quality of life grants, the assistive technology acts in the States, and Europe and Australia, I've known people to go through those processes to get all these covered through their government support programs for everything that's on there.

[00:20:55] I know the PhoeniX is in China and Japan, Germany, and Italy right now where there's users, both clinical as well as individuals. And then here in the States being used in clinics as well as individual users. ReWalk and Exo and Indego, they're all out in clinics as well. Different clinics have access to multiple. Some just have one because of the expense of putting them in. The ReWalk, the PhoeniX is the lightest. It's modular. It actually comes in three parts so you can, it's sitting on the box that it comes with. So big Pelican padded case so that you can take it with you. It is medical, so it doesn't count as baggage. But it weighs about 30 pounds with shoes, 27 without. And it's the least expensive of all the exoskeletons right now at 65,000. So still pretty pricey but once we get the Medicare approval, no more than some of the custom power chairs.

[00:22:19] **Roberta Pesce:** Right, right. All right. Well, Sandy, thank you so much for this incredible talk. We really appreciate you being here, and I'm sure that you'll join also during the event and get on and maybe you can answer some questions there as well and connect with others.

[00:22:37] **Sandy Hanebrink:** I will do that.

[00:22:37] **Roberta Pesce:** So, thank you. Wonderful, thank you, Sandy. And to all of you, we have a 5 minute, I believe, now break. Please head over to the connect and learn area to meet some of our community partners. You can also meet us at SRNA. You can meet our sponsors as well if you'd like and we'll be back in 5 minutes or so with the next talk. See you then! Bye, everyone.