

Kessler Foundation Podcast Transcript: Uh-Oh the Sky is Falling: Emergency Preparedness for People with Spinal Cord Injury

Recorded August 2019. [Listen to it here.](#)

ANNOUNCER: 00:06

[music] The likelihood that you and your family will recover from an emergency tomorrow depends on the planning and preparation done today. In this Spinal Cord Injury Grand Rounds podcast, Robin Bischoff, Nurse Manager of the spinal cord injury unit at Kessler Institute for Rehabilitation presented Uh-oh, The Sky is Falling: Emergency Preparedness for People with Spinal Cord Injury. This presentation was hosted by the Northern New Jersey Spinal Cord Injury System, which is supported by a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research, NIDILRR grant number 90SI5026. NIDILRR is a center within the Administration for Community Living, Department of Health and Human Services. This presentation was recorded, produced, and edited by Joan Banks-Smith, Creative Producer for Kessler Foundation on Thursday, August 15th, 2019 at the Kessler Institute for Rehabilitation Conference Center, West Orange, New Jersey. Be sure and download the presentation slides, which includes emergency preparedness worksheets, lists, tips, and items to build an emergency to-go bag. The link for the slides, along with other SCI Grand Rounds podcasts, can be found in the description of this podcast. Get ready now. Be prepared. Listen in as Jeanne Zanca, Senior Research Scientist at Kessler Foundation, welcomes Robin Bischoff.

JEANNE ZANCA: 01:43

Welcome to all those who are joining us in person, and we also are being joined by a number of colleagues remotely. So we're glad that all of you have joined us. My name is Jeanne Zanca. I'm a senior research scientist at Kessler Foundation, and I'm so glad we are joined today by Robin Bischoff, who is the nurse manager for our SCI inpatient unit. She is also a prominent leader in a number of SCI organizations. She is currently the president of the spinal cord injury nurses section of the Academy of Spinal Cord Injury Professionals and on ASCIP's board of governors and also has been a leader for many years, including president of our local chapter of the Association of Rehabilitation Nurses. And I'm very glad to welcome Robin here today. [applause]

ROBIN BISCHOFF: 02:27

Today's program is being presented just to get everybody thinking about what would happen if disaster was going to come. You have to think ahead. There's no way I'm going to be able to give you information to tell you what to do. But we also have to start thinking about our patients. Our patients' life have changed. They've lost the mobility. So even if they had a plan ahead of time, their plan has now changed. 2017 was the year I started thinking about, "How are we going to help our patients survive a disaster?" 2017 because so many things happened, and during a meeting, Dr. Kirshblum said, "Can somebody start thinking about making go bags?" So that person was me. So for the conference in ASCIP in 2018, I decided to do a disaster planning. Oh, here we are. I was waiting for this to come up. So during ASCIP, which was in Colorado, nice and safe in 2017, prior to getting there, there was Hurricane Harvey. As they mentioned, I was a member of the nursing board. There's nine of us. Four were from Texas. They couldn't make it because they had to stay with their hospitals. Also, we had United Spinal President from Houston as part of the governor's board. He started to talk to us about the spinal cord patients that were in shelters that had no wheelchairs. They had no catheters. So at our registration desk, we had to put a

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donation box out, and then we started to think about, "How can we get the supplies to these people that need them?"

BISCHOFF: 04:05

So that was Hurricane Harvey. While we were at the same conference, I lost some more board members to Florida because Irma started. After Irma, my last board member that wasn't from New Jersey - I had one from Kansas - was from Puerto Rico, and she had to leave. That left me, one, and one other person out of a group of nine. Three hurricanes in a row. Our following conference was scheduled for New Orleans in 2018, and this is where I gave the talk. Preparing for 2018, we took insurance out because it was New Orleans, and we were afraid after all these hurricanes. So also in 2018, we had the California fires, a volcano eruption, New Jersey floods, hurricane in Hawaii, and does anybody know what that's a picture of? In November of 2018, we had a snowstorm that we were going to get a little bit of snow. So those of us that were here for the day and the night realized we couldn't even get out of Pleasant Valley Way. You couldn't make a right turn out of our driveway. We had outpatients that were stuck in our building. So we were a rehabilitation hospital, and we're able to take care of our patients. We had people come in to use our bathrooms because they didn't have anywhere to go. I now keep medications in my desk because I didn't expect it to get stuck here that night. So we always have to plan ahead, and that's what the entire literature says. Plan ahead. Think about what can happen because you're never going to know. That is 2037 from the window.

BISCHOFF: 05:53

So so far in 2019, we've had excessive heat, not just in the United States, but throughout the world. So we know, especially after spinal cord injury, how that can affect our patients. Anybody. We had tons of deaths that weren't spinal cord injured, but our patients have to be educated as to keep themselves cool, and in reverse too. If it's snowing out, to keep themselves warm because if they have an injury of T6 or above, they can't sweat, so they can't regulate their temperature. We also had, so far in 2019, a lot of black- and brown-outs. The patients that use electricity would have to think of an alternative. And then Springfield had a tornado. So hopefully, the sky is never going to fall, but we have to plan because the weather is changing and disasters are happening.

BISCHOFF: 06:45

2012, that was Hurricane Sandy. That's my house. Some like saying you never know what's going to happen to you. I was here for, I believe it was, four days because we weren't allowed to go. So following Hurricane Sandy, the next day was a snowstorm. So my house was literally split in half. There were four family members home. Somebody was in that bedroom where the branch is. Luckily, he dove under the bed. So I got a phone call saying that my house was literally split in two, but I was stuck here. And I also had a 100-year mother close by, so I was panicked, and after that, I had no communication with them until I got home four days later. So maybe I could've planned on some way to communicate and I hadn't, but I was lucky. So in my house, I said it was split in two, so I finally got home. I knew I wasn't going to come back to Kessler for a while. It snowed. I left here in summer clothes. My winter clothes were in the attic. I couldn't even access clothes. But I was able to go to Kohl's, get new clothes. I had an insurance company that after a couple weeks of no electricity, snowing in my house, no way to cook, they put me in a lovely apartment

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for a year. And this year, I have to put a plug for Select Medical because when there's a disaster anywhere in the Select Medical family, if you go onto the portal, they tell you to please keep so-and-so in mind and then to also donate. So Select Medical helped me get through the beginning of it before the insurance company kicked in. So it's a real thing, so. I benefited from Select Medical helping me through this.

BISCHOFF: 08:20

So flooding is a problem in most disasters. When you're driving up to a large flood, people tend to think, "Oh, maybe I can make through it." Just a month ago, there was something on the news. EMS got to people and watched a mother and son drown in a car. So for us, even as well as our patients, if you see a flood, don't drive through it because chances are you're not going to make it, and flooding is very common. I just put in about the fire - 14% of fire victims are those with impaired mobility - because I couldn't get a statistic on just impaired mobility, but we know our patients are at risk because they're not moving the way they used to.

BISCHOFF: 09:04

So emergencies and disasters strike without warning. We saw pictures of Hurricane Harvey, and that, I think, is the most recent that showed us that our government isn't prepared to help our patients. They try. If you go onto websites, FEMA, they tell you disasters plan-- there's a hundred items on disaster planning for the disabled, but when it comes down to reality, it isn't helping. We need to help our patients prepare with the government of what they're going to need to survive. So this entire lecture is going to be about getting ready and be prepared ahead of time. So everyone needs a plan. We decided to educate our patients after spinal cord injury and decided to do it in three steps. We're starting a new education program. It's going to be more peer-directed. So there's a section on going home, so that's the way we're going to introduce it to our patient. At the end of that lecture, we're going to show them some slides and a video, just like you guys, to just start thinking about it. We can't tell you exactly what to do, but to start thinking about what you would do, what's in your area, and just to get the thoughts. The second step is we're going to go into their room and we're going to help them make a plan. You're going to see going forward, there's tons of forms that I have. I haven't decided on really one I like yet. We're trying to make our own, but right now, we give them an option of what forms to fill out, go in the room, and try to sit down and figure out what their plan would be, just to start it. And then the third step is giving them a bag with some supplies they're going to need. If they're using catheters, catheter supplies. I have a blanket in there. I just thought about something inexpensive I can buy. We can add whistles to the bag. But in the bag, there's also more forms on what you need to put in your bag, what you need to survive, and that's coming forward.

BISCHOFF: 10:54

So that's basically everything I said. I didn't talk about databases. So along with the filling on the forms on the plans, there's databases in every state. So New Jersey, I actually found one, and there's also a [911 National?]. So we have to find out where our patients are from and help them register so people know that they need assistance in getting out during an emergency. All our patients go home anyway. We tell them to notify the local authorities to let them know they have mobility issues, but this is in addition too. And then our goal is after we give them the go bag and they're gone a month, give them a phone call, and to see if they know where their bag

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is and what it's for. Going forward, this is the actual education that our patients receive.

BISCHOFF: 11:39

So it's your responsibility to help your patients and it's your responsibility in your own life to be prepared. You know what you need. We have to help our patients learn what they're going to need going forward. The likelihood that you and your family will recover from an emergency depends on the planning and preparation you do today. So this is everything we're talking to our patients-- again, it's just to get everybody thinking that it can happen to you and what can happen to you. So geographically, where do you live? Are you going to have tornadoes? Are you going to have hurricanes? Are you going to have snowstorms? Are you going to have earthquakes? Our patients need to start thinking about what they're [gullible?] for.

BISCHOFF: 12:18

The best place is to stay put. West Orange was a perfect example last year where our students got stuck in the schools. If your house is safe, stay where you are. Next best is go to a friend or go to a family if you can get there. The last option is to go to a shelter. If you feel like you have to go to a shelter, we suggest to our patients that ahead of time, before a disaster happens, go see the shelter. Go tell them what you need so they can prepare for you. Who's going to help you? Make sure there's a form of communication. I don't have an answer for this. If the cell phones aren't working, if the phones aren't working, how are you going to get help? I don't have an answer for it. Maybe somebody else does. Know who you're going to call. Have them look for you if something's happening and you can't get in touch with them. Have them look for you. And don't forget your pets. And what do you need from day to day?

BISCHOFF: 13:16

So I just added this slide. This wasn't in the original because we have had all the heat this year and heat is extremely important to talk to our patients. We have signs all over the unit about to stay out of the sun. And there's also been a lot of thunderstorms, and we have to watch for lightning. So create a support network of people to assist you. So I just said that before. Look at people you work with if you don't have family. Just make sure you're prepared ahead of time for it. Keep a list of emergency numbers. There's another slide in here, literally a thousand pieces of paper if you really wanted that you could possibly need in emergency to keep in a safe place. Contact local [emergency services?]. They keep a list of people who have disabilities, and yes, there are a lot of them. Know the location of the nearest shelter and if it's accessible, and make sure you go there and look at them and tell your needs. But remember the safest place is staying put.

BISCHOFF: 14:14

This is a new form that I just found when I was trying to edit the lecture. This is from the University of Washington, and this is the best form I've ever seen. I have a hard copy on the table, but it literally, besides helping people make a plan, it tells them everything they need, and it's a great form. It asks them about functional ability on it. So I have a separate form for that that I'm just going to-- it's up here. You just have to go into the University of Washington and it pops up. This is all from them. This is the one we had in our kit and this is the one we're presently using to help people devise a plan and what they're going to do. So it asks for medical conditions, medications. How do people have medications? We tell them to put a few days' supply into the go bag,

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but then they expire. Trevor's not in here. I had asked him originally, "What do we do? How do we remind people?" They're just going to have to remember to check their medications every so often to make sure they haven't expired or know every three months, replace them and change them. I talked about how I got stuck here this last storm, and I'm on medication now. And I was thinking as I'm doing this, "Wow. My meds have changed, but I haven't updated what's in my drawer if I ever need it." I'm literally just going to go through these because these are just forms. I like this one because this says, actually, what a person can do. But that's included in the University of Washington too. But if you don't speak for yourself, people aren't going to know what you can do. If I had to go rescue you, I wouldn't know you needed to be fed. So you need to let people know what you need.

BISCHOFF: 15:50

So the go bags. I have two here that you can look at. One is for somebody with catheters. One is for somebody with intermittent catheterizations. There's a hundred forms online. You'd have to fill your whole house with emergency supplies if you'd listed everything you could possibly need. We'd like to keep everything in a bag, but if you have a spinal cord injury, there's supplies that you're not going to be able to get. So we have suppositories. We have [enemas?]. Just think of things you wouldn't get in a normal shelter. Heavy-duty gloves. I liked that on one of the sites because if you're using a manual wheelchair and you're going through glass or something, you need to protect your hands. So this is what we show our patients. The next few slides are literally just things you should put in, and so the obvious, food, water. I love the whistle. I didn't put whistles in our bag, but going forward, I found a website that has a whistle and a flashlight in one, so I'm going to start putting those in the bags. But whatever you would need. So this is where we actually sit with our patients after we present it individually and tell them what they're-- help them decide what they're going to need. It's just a start. This is what I talked about. It's called the notebook. It's all documents and documents they suggest that you should keep in a safe place, like marriage license, things you wouldn't think of, pay stubs, your prescriptions, but I liked that. Of course, I don't have it. So this is an example of the databases to sign up. That's the New Jersey one, and this is the national 911, and everything can be found online.

BISCHOFF: 17:38

So for the conclusion of it is everything is plan ahead, plan ahead. The government has a lot of programs out there, but the best practice is going to be the government working with healthcare professionals because they don't know what our patients need. We know what our patients need. So we need to work together to make a safe plan. This is given to our patients, as well as other resources. So this was really fast. It was a half hour at ASCIP and I guess I did it in just under a half hour here.

BISCHOFF: 18:11

But last night, I was trying to update this a little bit, and I know when I first did my very first presentation, I saw a picture that I loved, but I wasn't techy enough to get the picture into the slide. It was a picture of a young boy pushing an older person in a wheelchair through a storm. I said, "That would be great. Now that I have Courtney and I have Jeannie who can do the techy stuff, I want that in here." So I'm sitting in bed - and I got home really late from work - and I'm looking and I'm looking and I'm looking. And I can't find anything. So I start putting searches in, people in wheelchairs

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being rescued, rescuing spinal cord patients from a storm. The first thing that came up was something awful that-- or actually, it was something wonderful awful that happened about a month ago. Was an amputee was saved by a 16-year-old who was with his mother and his house somehow-- some kind of disaster, and it shows you the 16-year-old saving this person, but that's not what I wanted. I wanted this original image that I saw. And I keep putting in searches, and I'm an animal person, and I get all these cute, little animals being rescued and these dogs. No. I want people in wheelchairs. And there's a person in a wheelchair here and there, and I keep going and I keep searching, and I'm changing the words, and I'm still getting all these animals. I'm like, "Is it because I selected an animal first that the dogs are just coming up?" and I'm getting really, really frustrated because then I put spinal cord injured people being rescued from a storm, and what do I come up? A dog with the wheels behind them and the goats with the wheels behind them. And I go into Brennan's room, my 19-year-old son. I said, "I can't do this anymore." I said, "I'm tired. I want to go to sleep, and I'm looking for something. What am I doing wrong? Why is my tablet just showing me pictures of animals?" Jay, you're looking at me and you know how techy I am. What was I doing?

AUDIENCE: 20:04

[inaudible].

BISCHOFF: 20:05

Does anybody know what I was doing? I was using the word rescue. And people weren't coming up. Animals were. Okay. Thank you. [applause]

ANNOUNCER: 20:22

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