

## EFMP & Me Podcast, Season 2, Episode 5: Safety and Emergency Considerations

## Transcript

- [Jen Wong] Do you have concerns about your family member's safety during emergencies at home, in the community or even during a natural disaster? What steps can you take now to prepare? We've got great tips and advice in today's podcast episode for families enrolled in EFMP.

I'm Jen Wong and today, we're talking about safety and emergency considerations.

- [Jen Wong] Hi, and welcome to the EFMP & Me podcast brought to you by the Office of Special Needs and Military OneSource. I'm Jen Wong, program analyst with the Office of Special Needs, and your host for today's episode. This podcast series highlights a variety of topics that can be further explored by visiting EFMP & Me on Military OneSource. EFMP & Me is a digital tool that provides valuable Exceptional Family Member Program-related topics, resources and checklists to service members, families, providers and leaders 24/7.

Today, we're going to talk about a very important topic: Keeping your family and your family member with special needs safe at home and in the community in the typical day-to-day, and prepared for any unforeseen emergencies. And to help us, our guest is Scott Campbell. Scott, I'm so pleased to be chatting with you today. Could you please share a little about yourself and maybe a little bit about how you got involved and became an expert in the safety and emergency considerations?

- [Scott Campbell] Jen, sure. Thanks very much for the introduction. I was in the Army for 31 years, and I'm on the boards of two of the local largest nonprofits in Northern Virginia when it comes to autism, and as part of those organizations, I've done over 400 safety talks about a third of those for local law enforcement. How I got into that was, I have a 23-year-old son with significant autism who's nonverbal and has a few minor behavioral challenges. And my concern that he would someday, almost the inevitability that he would be involved in some sort of law enforcement situation, which turns out, yep, we've already had three contacts with law enforcement, and both my concerns and also of some friends of ours who have a son about the same age also, who's kind of a Houdini in getting out of the house. They've got a mechanical lock on every door and window, and an audible alarm in every door, and a six-foot high fence all around their house.
- [Jen Wong] Wow.
- [Scott Campbell] And he regularly, in spite of all of that, is able to get off the property. So those concerns, and initially one of the local law enforcement agencies contacted me



and said, "Hey, we have this new thing called Project Lifesaver," which I think we'll talk about later on, "and we can find folks with autism, but once we find them, we don't know what to do with them." So my very first presentation way back in 2005 was, "OK, once you find them, this is what you do with them."

- [Jen Wong] Wow. Wow. Great. Thanks for sharing that, Scott. It sounds like your personal experience and professional experience are going to lead to some great ideas and tips for our listeners today.

And so hearing your background, Scott, I know you'll be speaking from your experience, not only as a subject matter expert, but as a parent, too, right? So it sounds like we may hear you refer to stories or situations related to your son, who has autism. And I just want to remind our listeners that the tips, the tools and the resources we discuss in today's episode are applicable to a variety of special needs, ages and particular concerns. And also each family is unique with different needs and different things that work for them, so what we talk about today may be suggested considerations, but only you can decide what really works for your family.

And I also want to recognize that what we discuss today may be a hard topic to cover. No one wants to think about their family in an unsettling or an unsafe situation. So if these topics are difficult to hear at this time, that's perfectly OK. You can exit the audio. Go directly to the list of resources posted with this podcast, and if you'd like to talk with someone right now, nonclinical counselors are available through Military OneSource 24/7. So Scott, there's a lot of great information that's discussed. I want to make sure we cover safety in the home and the community as well as emergency preparedness. So let's jump right in. What are some everyday things that you can do to keep your child safe in your community?

- [Scott Campbell] Well, as the parent of an adult with autism, I've learned quickly how important is to be proactive, and the first thing, of course, is disclose, disclose, disclose.
- [Jen Wong] OK.
- [Scott Campbell] You're going to need help. Statistically, that's just the way it is. So you need to get your neighbors involved, your community involved and work proactively. Have a "Get To Know Your Kid" barbecue party with your neighbors. We did that when we first moved to where we live now. Know they're approachable. Give them your phone number. So rather than calling 9-1-1, they can call you. Show them your child's ID bracelet or any other ID information that they have. When you're out on the road, display some autism awareness or notification items magnets, or license plates or stickers. There's a whole lot of those out there. Talk to your neighborhood watch program and also visit your local police and fire department with your individual with special needs so the first responders get to know them and they get to know your child.
- [Jen Wong] That makes sense. And I know when we talk about safety, I can see how knowing your surroundings, your neighbors and them knowing you can really be beneficial. But I'm curious, Scott, what do you think about disclosing to the people around you, who you don't know? So for example, sometimes I see kids at the mall with



their parents and they may have an identifying T-shirt that says autism or something like that on it.

- [Scott Campbell] Well, it kind of depends on the child. I mean, in the world of autism, if they're on the higher functioning end of the spectrum, it's probably not really needed. On the lower functioning end of the spectrum, and if they're a runner or an eloper, and particularly if they're nonverbal, you need to think a little more about disclosure, but you have to do it judiciously. Don't overthink it. With my kiddo who does a runner, these sorts of things happen. You're seven times more likely to have interaction with law enforcement if you have autism. So, again, you have to proactively plan for that near certainty.
- [Jen Wong] Great. I think it's a very important topic to think about, and it's definitely the parents' decision about when and who they want to disclose to, but what works for one family may not work for the next. But I'm thinking of one time where with this particular family, in this certain circumstance, I saw disclosure work. And if I could just tell this quick story, when my friends and I were at the park, a woman sat at a picnic table near us. She introduced herself and she said, "Hey, do you see that cute kid over there in the yellow shirt? That's my son. He's deaf. So if he's doing something unsafe, he won't hear you call out to him." And so you know what our response was to her? It was, "Oh, that's OK. We'll watch out for him." She never asked us to watch out for him. She was just disclosing that her child wouldn't hear us in an emergency, but suddenly she had about five or six other adults watching out for her child all from this disclosure.
- [Scott Campbell] Well, and one of the things with my son is, we never know what he's going to do. I mean, one of the things in his world is every French fry ever made is made for him, and if he sees a French fry anywhere, to him, "That's my French fry." And even if we're leaving any of those fine dining establishments, Wendy's, Burger Kings, McDonalds, and he's full, he's eaten, and as we're walking out, we've got to be really, really careful because he will snag a fry off of somebody's tray. He's done it oh so many times, and you use it as, again, a chance for disclosure, a chance for education. I apologize, say, "I'm sorry. He has significant autism. He's on a restricted diet. One of the few things he's allowed to have is potato products. I'll be happy to buy you a new pack of fries."

He's now 23. I've never had to do that because the usual reaction, once you explain it is, "Oh, OK. I didn't realize that. If he likes them so much, he can have my fries." As in, "Your kid just stuck his hand in my fries. I don't want them anymore." But if they give them to us, and they often do, we can't give him those fries because then we're reinforcing that behavior.

- [Jen Wong] Oh, that makes sense.
- [Scott Campbell] So, then we have to throw away, which are in his mind, his fries. So then we've got to get him to the car pretty quickly because then we're liable to have a little meltdown because we just threw away, which in his mind, are his fries.



- [Jen Wong] That's another great example of disclosure, and I bet a lot of parents may already be practicing that method because it's really just open and honest conversation. You're telling the other person, "Hey, it happened. This is it. This is the situation. Let's move on." But a great tip for keeping your community informed. What else would you recommend you can do to prepare when it comes to safety?
- [Scott Campbell] So, one of the things to do is provide a pre-notification system into the local 9-1-1 system. There's different ways of doing that. Some localities have what they call a smart 9-1-1 pre-notification system, which is done online. Some places have their own new unique system, including my locality of Fairfax County, Virginia. Get on your computer, put the data into it for your child, for your loved one regardless of age, and there's also what we call 9-1-1 flag sheets. They're called different things in different places where you fill out a piece of paper and physically provide that to your local law enforcement agency.
- [Scott Campbell] The key thing, whether it's done online or it's done using a piece of paper, is to make sure that in spite of just doing the notification, that your local 9-1-1 system has put something in the computer about your home, that your home is known as a location of interest, that they put some data into the computer to say, "OK, somebody with autism," or whatever the disability is, or if you have an elderly family member with you, someone has adults with dementia or Alzheimer's. But again, you want your home known as a location of interest so that when something happens and they bring your address up on the computer, they have a clue as to what's going on with that particular address.

Way back when, like 15 years ago, with our child, we went into the local police station, gave them a copy of the 9-1-1 flag sheet, because that's all that was available at the time, talked to the person behind the screen at the window there. Turns out she had a child with special needs herself. So we had some conversation. I watched her put some data into the system, and basically, it just said, "Child with autism at residence. Do not approach house with sirens on," because my son has hearing sensitivities. And then later on, talked to the lieutenant who was in charge of the shift that particular day and discussed what I was doing. He found out I was doing classes on autism awareness and safety. I went out and ultimately did a training with every shift at that local police station, and at the end of one of the days of one of the training sessions, one of the officers came up to me and said, "Hey, yeah. I know all about your son."

- [Jen Wong] Oh, wow.
- [Scott Campbell] I'm like, "Wow. How do you know about my son?" Well, as it turns out, he was the officer assigned to our neighborhood.
- [Jen Wong] Wow.
- [Scott Campbell] And he had a copy of the 9-1-1 flag sheet for my son in the book that he carried with him every single day.
- [Jen Wong] Wow.



- [Scott Campbell] And when he was taking his daily power ring break, that's what they call donuts sometimes, he read that and I quizzed him on it. And he really did off that two-sheet piece of paper really did know as much as there was to know about my kiddo. And for someone who has a child with very significant disabilities, I mean, that's as best as you can get. And that's where you hope your law enforcement would be. I'm sure by now he's moved on to a new duty station, but that's the Nirvana, when it comes to getting data into your 9-1-1 system and having your local law enforcement and firefighters and EMTs aware of what's going on at your house before they ever get to your house.
- [Jen Wong] I bet, I bet. This information, if families didn't already know it, this sounds so important, doing that pre-notification to the 9-1-1 system, doing that flag sheet so that way the local emergency personnel can get to know your family member. And like you mentioned, Scott, whether it's a family member with autism, difficulty understanding, who may panic in an emergency, or have a hearing or vision or communication impairment or a mobility concern, I could see a lot of different families taking advantage of this support that's put in place. So Scott, what sort of information do you recommend putting on one of these flag sheets?
- [Scott Campbell] Well, the one we hand out, it's a Word file. You fill out whatever it is that applies for your child regardless of what the disability is.
- [Jen Wong] OK.
- [Scott Campbell] And it's not just for children with special needs. It could be used for adults with Alzheimer's or any sort of impairment, deaf/hard of hearing, low vision, any sort of thing. But some of the things that you could put on the flag sheet is obviously a current photo of the child, physical description, height, weight, hair color, any other ID marks. In the world of autism where there's usually sensory issues, you want to talk about those and what they are and how to counteract them, if possible. Any medical or dietary issues, if they're inclined to run off where they might go, any compulsive behaviors they may have. For my son, it's hand flapping. Again, where they might run off to, their likes, dislikes, how do they communicate? And if they typically wear any particular identification, bracelets, necklets, or if they carry an ID card.

In the world of autism, water is a huge issue. For individuals that run off and unfortunately die, about 90% of them die by drowning. So it's good to know where all the local water sources are, and they need to be searched first. Another concern is fire. Unfortunately, many individuals with autism tend not to leave a burning building. They recognize that fire's a problem, but maybe not a problem to them.

So, one of the other things to put on the flag sheet is where's the location of the bedroom of the individual because typically in a fire, they will run and hide in the closet or behind furniture and not leave the building. So firefighters need to know where is the person typically going to go so they can rescue them, if they have to, out of that particular location. And obviously, contact information for parents, guardians, whoever it may be, emergency contact information, and this sort of thing can be shared and



should be shared with the teachers, again, your local fire department, police department. If you have a particularly helpful neighbor, give them a copy. With the school resource officers to school, give them a copy. That sort of thing.

- [Jen Wong] That all makes a lot of sense. Are there any other forms or documents that can be filled out with the local emergency personnel?
- [Scott Campbell] Well, many sheriff's departments have a missing child packet that they will put together, and usually these are at their open house sort of events. Or you can just go to the local sheriff's department and fill one out. Typically, again, it's a photo. They may take fingerprints, which for someone with autism can be a little difficult. Again, they take physical description, and in some locations you actually take a DNA sample. Now nothing's done with these kits. They simply get them. They store them, and then if you call them and say, "Hey, my child's missing," and then they pull the kit out, look at the information, and then use that, dispatch that information to all the law enforcement that are involved so they have an easier time looking for those individuals.
- [Jen Wong] OK. OK. And like I mentioned earlier, this can be a hard conversation to have. No one wants to think about their loved one in an unsafe situation, but being prepared is very essential. One thing, if I could just add, you mentioned earlier about having a current photo, and I'd even add to make sure it's an accurate current photo. I feel like nowadays in the land of digital photos, there's so many apps and filters. You have to take into consideration, "Is that photo still an accurate portrayal of that person? Is it recent? Is it accurate? Does it show those identifying characteristics of that person?" So Scott, would you be willing to share the story about how excited your son gets about a long blade of grass?
- [Scott Campbell] My son, I mean, amongst other things, his self-stimulatory behavior is spinning string or long blades of grass. And when he was about 6, we were down in Yorktown, Virginia and just walking along the road. I'm between him and the road with my hand on his shoulder because, again, we never know where he's going to go. My wife is between him and the James River, again, given the drowning situations. That's why that's key. And he likes to change what he stims with, what he waves around in his hands. And without any notification, he got out from underneath my hand, started running across the street, and I yelled his name because if I don't yell his name, he doesn't know I'm talking to him. And obviously, you loudly scream, "Stop!" Now he's a really compliant individual, and he immediately stopped. And that was good because the SUV that almost hit him was about 3 inches away from his nose.
- [Jen Wong] Oh wow.
- [Scott Campbell] The toe of his shoe was actually touching the tire of the car.
- [Jen Wong] Wow.
- [Scott Campbell] I pulled him back onto the sidewalk. He was very mad, not because he almost got run over in front of his parents, but because he couldn't get that long



blade of grass on the other side of the street. So again, you just never know how it's going to go.

- [Jen Wong] Absolutely. So in scenarios like that where you may have a family member who is a runner or elopes, tends to run off, do you have any recommendations of resources that are out there?
- [Scott Campbell] Well, one of the primary ones I tell folks about is the Project Lifesaver program, which is typically run by the local sheriff's department, but not always. It's a radio technology system, and it looks like a big watch and usually is put on the individual's wrist. They have an assortment of bands that they use due to sensory issues, and it's on the individual 24 hours a day, 365 days of the year. It's fairly water resistant. And it's a chance for, if the person does run off and elope, they notify local law enforcement, they show up with tracking systems, and how many they have depends on the locality. And they just dial in the radio frequency for that particular tracking band that's on the individual, and typically within 30 minutes, they're able to find them. Sometimes in five or 10 minutes. This was originally begun with adults with Alzheimer's, and then they started handling kids with special needs, too, of any age. And since 1999, they've found over 3,800 individuals using this system all around the country.
- [Jen Wong] Wow.
- [Scott Campbell] Now, part of the issue is that it's not everywhere.
- [Jen Wong] OK.
- [Scott Campbell] Your local law enforcement has to buy into the system. Sometimes they get grants to be able to do that. So, if it's not available, there's a number of other GPS systems that can be bought by the family. But I would go with Project Lifesaver first, if it is available. Number one, it causes the local law enforcement and you and your loved one to meet each other because the battery on the device has to be changed every month or two, depending on which battery they use. So they typically come to the house and talk to your child, get to know him or her.

Another hint is dressing the person in bright-colored shirts and coats in the middle of the winter. If they've got a really loud, brightly-colored Hawaiian shirt on, you don't put a dark colored coat over them because those don't really help a lot because, particularly in any environment, it's easier to find somebody if they've got brightly-colored clothes.

- [Jen Wong] Right.
- [Scott Campbell] By the way, Project Lifesaver actually sells a line of clothing that has the individual's name and ID number on the shirt. So particularly if the individual is nonverbal, if they're out looking and this person's got that shirt on, which you unfortunately have to buy, then they've got a positive ID of, "OK, this is the person we're looking for."
- [Jen Wong] Great resource, Scott. I would also recommend that families can reach out to their local EFMP Family Support office or their police department, their military



police, emergency personnel, even local organizations to find out if there are other resources available locally.

- [Scott Campbell] Yeah, and there's a couple of other additional hints. Again, I talked about drowning. So obviously, there's a need for adaptive swim lessons. So it's important to, particularly if you've got water anywhere around you, and many places we do, either a pond or a stream or a lake, getting the child, to hopefully teach them how to swim or at least float. A lot of localities have adaptive swim programs that are run by the county therapeutic recreation department. So that's something if it's available to try to use, or if you have to, get someone privately to be able to teach, hopefully, your child how to swim or float. Check the local state sex offender registry, which is usually run by the state police in each state. Just see if there's anybody by you that you just need to know about.

And I mentioned earlier, and then giving a copy of the 9-1-1 flag sheet to the local school resource officer, if there is one. Typically, they're in middle and high schools, not usually in elementary schools, and at least have them meet your child, if not, have them come to an IEP meeting because they need to know your child so they recognize them. Another thing to give them is if the child has a behavior intervention plan, I give them a copy of that because it gives them an idea of what to do, and more importantly, what not to do because the last thing you want to do, if someone is having a meltdown, is aggravate the situation with some sort of sensory issue that makes it even worse.

So, again, how to deal with the challenging behaviors. Sometimes there's local resources. Where we live, they have actually a medical department that's connected to the law enforcement, and if you have a challenging behavior, you can call. They have a team that's on standby 24 hours a day where you can take them, and they take them there, and there's folks on hand. It isn't a law enforcement situation. It's more of a medical situation, a mental health situation.

- [Jen Wong] OK.
- [Scott Campbell] And so, there's resources out there available, but again, you have to do the due diligence to see what's available in your locality.
- [Jen Wong] Absolutely, absolutely. It can definitely vary based on area. And like I mentioned, checking in with your Family Support office, they may be able to point you in the direction of what some of those local resources are. Scott, thank you for sharing this abundance of resources when it comes to safety. I think we've talked about preparing in your home and in your community to keep your family, including your family member with special needs, safe. I just want to transition a little bit and talk about emergency preparedness because planning and preparing are so important in any type of emergency, and knowing how to plan for your family member with special needs will help keep them as safe as possible. So, Scott, can you share your thoughts on how a family might put together, specifically, a family emergency plan or why?
- [Scott Campbell] Sure. There's lots of stuff to consider about that. One of those is what type of emergency you're talking about. It depends on the scale of the emergency, the



big scale or regional scale of if you have to leave your home, think Hurricane Katrina or something really huge, or fires that are happening in California now. You have to leave and you may never come back, ever. And if you do, there'll be nothing there to come back to. So, if you've got 10, 15 minutes to leave, what do you take? That's something you have to think about ahead of time because, in the moment, you may not take everything you really need. The self-stimulatory toys or favorite thing that your child wants and will help calm them down. Medical records, educational records, the things that are, besides your loved ones, which are going to be almost impossible to replace because you may never be able to get back to replace them. So that sort of thing.

That's the big scale, and then smaller scale, local. If there's a fire, whose job is to get the person with autism, or any other disability, out of the house? Well, everybody because, again, folks with autism tend not to leave a burning building. So, you need to develop the plan, know where the exits are, how far it is from their bedroom to all of those exits, and practice that plan. They do it in school. We do it at the office at least a couple of times a year. So practice that at home. I mean, where does everybody meet? Hopefully, it's some place that'll be dry, depending on the weather. So you get there, and if it's a child with autism, they also tend to be what they call a bolt risk. So once you get them there, you've got to watch them because, again, you never know what's going to happen.

So once they get these individuals out of whatever dangerous situation there may be, you've got to keep them out and you've got to watch them constantly to make sure they don't, in some way, put themselves back into danger.

- [Jen Wong] That makes sense, and I really believe in your recommendation to practice the plan because, like you said, we practice in school, we practice at work, and you mentioned, "Hey, I hope it's dry." I don't know about you, but I've done some practice fire drills on the installation at work where it was raining, it was pouring, and so that might even be a good recommendation to try that with your family member. What would happen if it was pouring and you practiced that fire escape? These are just some additional ideas. They're recommended for all families, really. But I think you may have hit some of them already, preparing for big and small emergencies, and also considering who may or may not be home. Will the service member be at work or deployed or at a training?

Create a network of support for backup in the event of a crisis or an emergency, and have an emergency fund available to get money, if needed. Involve all the family members in emergency preparedness discussions. You don't need to scare your family members, but you can calmly have that conversation to inform and to prepare them. And post a list of emergency numbers, even include an emergency contact out of state in the event that a local emergency, for example, a natural disaster happens, and develop a family emergency communication plan. How will you be able to connect and talk to each other, if separated?



Scott, you had mentioned, plan those escape routes from the home, set up a meeting spot and keep an eye on your family members, ensure they stay at the safe meeting spot. Keeping those important documents, including your insurance policy in a plastic bag, in a portable fireproof or waterproof box and some sort of method to be able to safely and quickly leave with those difficult-to-replace documents you mentioned, having a ready-to-go supply kit. I call it a go-bag, including things like the three-day supply of water, food, medication, battery, flashlight. Like you mentioned, Scott, those toys or those objects that your family member may be very attached to, and even the pets. If you can, create a pet plan. What family member is in charge of getting the pets, if time allows? Does the pet have a go-bag or spot in your go-bag that has the food and the bowls and the leashes and things like that?

And FEMA. FEMA has the ready.gov website, which provides a Make A Plan resources section with special considerations for individuals with disabilities. You can also find info on Military OneSource, and links to any of those specific resources will be posted with this podcast episode. There's also the Red Cross, various communication apps, installation and community alerts. I get those buzzing on my phone if anything ever happens, and your installation will also have an emergency family assistance plan and a family assistance center to assist during any emergency or disaster. And these centers, they can share how to get medical services, counseling, temporary lodging or transportation. So check in with your installation to know where that family assistance center will be in the event of a disaster.

So, Scott, that's my quick overview of some additional tips and resources in the event of an emergency. Can you think of anything else that I may have missed?

- [Scott Campbell] Well, one of the things on shelter locations, basically, if a child with autism or who has any sort of sensory issues, typically, they're not going to be able to stay at a large shelter. And so you need to tell the folks in charge of the shelter operation up front, and I've done some work with the Red Cross on this, that, "Hey, I've got a child with autism," or somebody else that has sensory issues. So typically, they will find a hotel so you'll have your own room. You won't be put in the big, massive shelters. But it's something you need to tell them up front. Again, it all goes back to disclosure about what's going on with your family.

And every time you PCS, of course, you have to update the local Exceptional Family Member Program system and keep them informed of any changes there may be. Each time there's a deployment or PCS, any time there's medical changes,

- [Jen Wong] Absolutely. Absolutely. And I think military families, including military families with special needs, may face some additional challenges, such as what you just mentioned with deployments, PCS, medical changes. And so maybe the service member is even a geo-bachelor on an unaccompanied tour and the family is living somewhere else. So there's a lot of different scenarios that families may find themselves in, but what I'm really hearing, Scott, is that preparation is key and communication is key, really expressing what your family and your family member's needs are to get that assistance.



So, Scott, we've talked about some terrific ways to keep your family safe every day in your community and also during emergencies. Do you have any final thoughts you'd like to share on safety?

- [Scott Campbell] Well, I mean, safety concerns are a challenge, particularly for families with special needs, and you need to proactively think about it, prepare for it, because again, it's not a matter if something's going happen. It's when, particularly in the world of autism. So there's things you can do and you have to do up front to increase the chances of those challenges resulting in better, safer outcomes for you, for your loved one, for everybody, including your local first responders.
- [Jen Wong] That makes sense. Scott, thank you again for all the wonderful information. This has been a really great discussion. And I want to thank our listeners. Please pass this information on to others who may benefit. Be sure to check out EFMP & Me. We do have a specific checklist called "Preparing for an Emergency," and there's more information there, as well as you can review the list of resources that we post along with this episode. So keep in touch with your EFMP Family Support providers at your installation for any assistance when it comes to safety and emergency planning or any questions you may have about the Exceptional Family Member Program. Scott, thank you again for joining us.
- [Scott Campbell] Well, thanks very much, and stay safe out there.
- [Jen Wong] Absolutely. Thank you.
- [Jen Wong] You've been listening to a podcast for families enrolled in EFMP brought to you by the Office of Special Needs and Military OneSource. Come back to catch our episode on Preparing for Deployment. I'm Jen Wong. Thanks for listening.