Webinar: TFL AAC

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Carolyn Phillips: Hello, everybody. Thank you so much for joining us today. As we explore communication options for folks who are in the hospital. This is part of a series that we're doing in direct response for what's been affecting folks throughout the world related to COVID‑19.

We often try to take a proactive approach when trying to address needs and think about the whole "nothing about us without us." We have heard your requests and I'm very happy to have Liz Persaud who is a national leader in the world of assistive technology to be able to join us today and guide us through this process of this discussion and this learning opportunity and also have DeeDee Bunn who is also nationally recognized as a speech language pathologist in this world of how do we communicate effectively especially when it matters most. So I will turn this over to Liz. I'm very happy that we also have outstanding captioning by Heather who is on our team. So Liz, take it away.

Liz Persaud: Thank you so much, Carolyn. My I'm Liz Persaud and I'm thrilled to be bringing you the information today in today's webinar. We are thrilled to be talking about such an important topic that's focused on communication when hospitalized. I wanted to just quickly say that a lot of these webinars in these series are a direct response of the folks that we're working with in the community. And what is it that people want to hear now. This is something that none of us no matter what your everyday lifestyle is, what your ability is, this is something new to everyone. I think everyone no matter what your current situation is ‑‑ they're worried about their health and what does this mean for, you know, if we get sick and are hospitalized and what does that mean. So as somebody who is actively living with a neuro muscular disk, communication is something that is very important. I live in the space of using technology every single day. And I am thinking about further on down the line especially when it comes to this virus COVID‑19 and what does that mean in the long‑term.

We are excited the Tools for Life team to be pulling together these resources. As Carolyn mentioned, we are responding to the COVID‑19 pandemic by collecting and vetting resources not only for individuals with disabilities in the community but also for their family and their circles of support.

All of the resources that you're going to hear about in today's presentation, these are meant to empower you. These are not meant to replace advice or instructions from your doctor or medical team. We are here to share resources in the assistive technology and disability arenas. Just so that way everyone is familiar with them. We encourage all of you no matter what your role is as you're listening to this webinar to take this information, do further research and share what you learn with your medical and support teams. All of the presentations and resources are accessible. They will be posted on the Tools for Life website and we ask you share this information with anyone that will benefit. We want to get this out there in the hands of anyone that can benefit from this information.

Keep calm and stay smart. We are all in this together and together we are stronger. We encourage all of you to stay in formed, stay safe and stay educated.

So as Carolyn mentioned, I'm very excited that DeeDee Bunn who is our speech language pathologist on the Tools for Life team is going to be bringing you the bulk of the information today. DeeDee has been doing lots of research and collecting lots of amazing information when it comes to various methods of communication, especially when you're in the hospital. So I think a lot of this information will be enlightening and reassuring especially when going through uncertain times. I wanted to share information with all of you when it comes to contacting your state‑wide assistive technology program. As you know, we're with the Tools for Life program. We're here in Georgia and serve all individuals of all ages and disabilities here in Georgia. We encourage you to visit the AT3 center website and find your state‑wide assistive technology program. Here's the website link and a screen shot of the website. We encourage you to reach out to your local community program and talk to them about some of these resources, as well as assistive technology and any of those supports that you need to help yourself to be more independent, especially during these times. They will be able to help you out.

Some, with that being said, I'm going to toss the microphone over to DeeDee.

>> DeeDee: Thank you, Liz. I appreciate that introduction and all of the good information you've already given. This webinar is going to be focusing primarily on addressing a loss of communication when you're in an emergency situation. There are lots of people out there that depend upon augmentative communication as their primary means of communication. With this webinar we'll talk about people who do not have a loss of communication but may experience one when they're in the hospital. One of the things that happens often when you're in an emergency situation is you're not in control of your communication and you may end up with medical devices that prevent you from communicating. When we look at the levels of care in a hospital, you're looking at basically 5 different episodes of care starting from the emergency room going to intensive care and then and possibly to a step-down unit and a regular floor and then outpatient. This webinar will address the communication strategies that may be used in the first 2 or 3 levels. We'll focus on low tech communication systems that can be used in that kind of situation.

When you're in the hospital, your communication is going to be affected by a lot of different things. This information was provided by Debbie McBride in another PowerPoint that I found called augmentative communication tools for medical settings. When there is trauma, that's going to affect everything in your life. You're going to be in an environment where communication is very rapid. Doctors need things quickly and nurses need things quickly. They won't be able to spend a lot of time in an emergency situation because critical decisions are having to be made. The individual that's in the situation is going to have some degree of pain or discomfort which could affect their communication. They may not have different things they have used to help with communication such as hearing aids or dentures which could affect their speech, or they may not be able to see things because they don't have glasses. Also if they are on medication they may be drowsy or as a letter as they could be. So the positions for communication are not always at their optimal settings. There may be other things that may happen. Because of those factors, there are elements that you want to look at for AAC and hospital communication that have to be considered. First of all, is the element of necessity. The communication that's happening in those environments are going to be communication that's very necessary to get information to the doctors and nurses and staff that are working with you. So communication also needs to be functional. It needs to be something that addresses those issues. It's not something that's going to be a long communication process. It has to be easy to access by the individual having the loss of communication and also by the caregivers that are taking care of them. Which goes into the fact that it needs to be easy to use and acquire. It needs to be something that can be set up in the room and quickly and easily given to the person that needs to communicate and use bide the staff working with them.

So what kind of communication tools do we want to look at to be used in that kind of setting?

There are a number of different tools that we can consider. First of all, we want to be able to develop a plan. If you feel like you're going to be going into the hospital, and you may have a loss of communication, we thought about this a lot with COVID‑19 because often individuals that are going into the hospital are individuals that are in some type of respiratory distress. So the tools used for support may prevent them from communicating. So you want to create a plan. So first have a support team. Who is going it be a support team while you are hospitalized? It may be a caregiver that you're used to, it may be your husband, your child, a friend. Anyone that is familiar with you and can help you with communication while you're in the hospital. So once you identify the people that could be your support team, then you can also determine how you want to communicate. What is the way that's going to be easiest to communicate? One of the things we often fall back on is a yes or no response. That's a quick and easy way to communicate when somebody wants to know if you're in pain, do you want something to eat or drink, are you having trouble breathing. All of those can be responded with a yes or no. You want to determine how you will respond to that. Are you using a head nod or a thumbs up or down? Those are ways to think about how you will respond to the questions that the nurses and doctors need to know.

The next thing you want to think about is how ‑‑ what are you going to need to communicate? What things do you need to communicate about? What vocabulary do you need to do? And then the method that the hospital team and staff are going to talk with you about using either yes, no questions, communication boards, spelling board, you might have a pain scale and body parts on there and message to support like partner assisted scanning and have written instructions on what you decided will be a way to communicate. We will address all of those different things as we're talking through the next several slides.

First of all, the person that's going to be your support team, do they know what you want them to do if you're in a situation where you lose the ability to communicate? Hopefully that is on a temporary period of time. The other thing that you need to be aware of because we know things are changing very rapidly in the hospital is if it is due to COVID‑19, you need to find out what the restrictions are that the hospital may impose because of the things that are happening in these unprecedented times. You may want to find out if they will allow you to bring in something into the hospital. If you're using technology or tools at home, will they let you bring that into the hospital setting and if so, how does that need to be sanitized. That may also apply to communication boards that you to bring with you. I suggest boards be laminated so they can be easily sanitized if they allow you to bring that in.

When we talk about yes/no, look for a consistent way to respond. If you are able to do a motor response such as nodding your head or raising your hand that's the easiest way to do that. One of the things is used is eye blinks. When I talk to people who work in ICU's and work with communication, often they tell me it is best to just respond yes and then no response is considered a no. So that takes less effort on the part of the individual that is trying to communicate and that can be something that is very clear to the caregiver that if you don't do anything, that's no. If you do an eye blink or head nod or thumbs up that is yes. So eye blinks or head nods or shakes, raising your hand or finger or thumbs up or down that's almost a universal way of responding. You can also if those are not possible think about another consistent movement that you may have. I knew one individual that used shoulder shrugs for yes or no. Those are ways to respond to questions the staff may ask you.

The other thing you need to find out is what you need to say. You need to talk about your medical needs, what kind of pain you may be having, whether you're hungry or in pain, whether you need to contact a family member. All of those things are important for nursing staff to know. Personal needs of whether you need to be shifted in the bed. Personal information is something that you need to communicate with a doctor or nurse about specific things. What level of pain you're experiencing and where that pain is another thing you may need to be able to do? One of the things you want to have access to is a spelling board. One of the limitations of communication boards is that they can only hold so much language. If you have a spelling board, then your ability to communicate things that are not on that communication board expands greatly.

There are different designs of communication boards. What I want to do in this presentation is give you some examples of communication boards that are easily available. These are not the only communication boards that are out there, but they are some of the ones that have been designed and easily available to you. At the end of this presentation I will have two slides with links to all of the boards I presented here so you are able to access should you want to download or look at them to see if they will meet your needs. When looking at communication boards and their design you see two here. The left-hand side is a symbol base communication board. The one on the right is a text base communication board. If you are an adult, typically an adult will use a text base communication board. However, there may be times you may want to consider using a symbol base board that it may be easier to quickly locate and see the message you want to communicate to the doctor or nurse. Than having to scan through and read all of the boxes on the text base communication board.

That is a personal choice, and which one works best for you. You'll also notice they have different areas that are color coded. If you look at the one on the right-hand side there's a top left-hand corner is a reddish or pink. That is sensory types of things. Pain, hot, cold, tired. Then beyond that there's the green area that talks about environment things like the TV control or a call button or you need your glasses or lotion applied. So each one of these areas makes it easier to find the different types of things you want to communicate by color coding. You'll also see on the bottom there's a yes/no. There's a not sure which I think is very important. There's also a box that says ask me a yes/no question or spell. So if you need to go to something else that is not on that communication board you have a way of telling them what you need communicate further.

We also have different levels of spelling boards. These are two different ones that have an ABC order for the spelling boards, as well as numbers on them. You see on the left there's also a silhouette of a body. One of these is a black and white and one is a blue background with white text that would be a personal preference as to which works better for you in order to be able to see it and access or point to or scan through these with your communication partner.

The first two or ABC order. Those are most frequently used. You can get alternate designs. The left is the frequency and numbers for listener scanning. If you go from top to bottom and scanning across the rows those are the most frequently used letters or numbers and will speed up access for communication. The one on the right-hand side is what they call an AEIOU board. Vowels take up what we spell. Almost everything we spell has vowels in it. So that will help you speed up your spelling as well. You can have an A row, an I row et cetera. That will help with the partner assisted scanning that I will talk about later and allows the vowels to be access to speed up communication.

You also have pain scales or body part boards. These are two examples of different ones that you can do. On the left-hand side is a communication board from widget health. This one is a nice board because it not only has the different silhouettes to represent the body pain and it has a representation of the pain scale. It also talks about the duration of pain and how long has it been going on, if the pain has been going on before, how frequently that pain comes about and what type of pain. That could be very important to your caregivers to know. The one on the right-hand side is a more simplistic and you have two silhouette and then you have intensity. You also have the communication right next to that as well.

Once you decided what type of communication board that you want whether it's a spelling board, a communication board or a pain scale board or a combination of all of those, you have to think about how are you going to access that communication, especially if you are bedridden in an ICU where your normal accessing methods may not work as well.

Typically if you're going to be able to reach out and touch that communication board, then you will use that. That can be the most direct and easiest way to do that. Often when you are sick enough to be in intensive care type of hospitalization, your ability to access something may have changed. So one of the ways we can provide access to those communication boards is through partner assisted scanning. This is a way that you would have a communication partner to help you when you can't communicate by pointing. That partner will basically go through the choices on a communication board starting at the top left-hand corner and going left to right and top to bottom, highlighting rows and items in the row. Once the item that you want to communicate has been highlighted either by the individual that's your communication partner is saying the item or pointing to the item then you indicate which one you wanted with a yes or an eye blink or a thumbs up whenever the item you want to communicate about has been reached. That is a very simplistic way to talk about partner assisted scanning. If that's a way you think you may need to communicate that way in a hospital, you may want to practice that with your support person and give you practice.

There are resources online that you can go to that give examples of partner assisted scanning. These next two slides will give you some links into some videos that will show this. The first video is introducing partner assisted scanning for spelling. This is from Boston children's hospital ALS children's communication program. They have a lot of wonderful resources on their website and this link will take you to them. This is a short video of how the partner will go through the AEIOU board and how the person communicating needs to respond. This next link that I will give you is a more in‑depth video that talks about partner assisted scanning and using specifically an AEIOU configuration. It will give you a lot of information on partner assisted scanning itself and give you examples of how that could be used in a hospital setting. So these are very good resources if you are considering partner assisted scanning as an access method when you are in the hospital.

Another method that you can do is eye gaze boards. Eye gaze boards are boards that have 6 different quadrants of letters and numbers that the individual that needs to communicate will gaze at or look at through an eye gaze board. If you look at the photograph in the top left corner you will see a woman, probably a nurse, working with a gentleman who is using eye gaze. He is able to see the person's eyes and where they are looking at in the communication board and she has a mirror image on her side to be able to see what that person is looking at. There is a strategy for using an eye gaze board so that you can specifically find the letter or the number that you need in each one of those quadrants. It's a 2-step process that helps identify the letter or number. For example, on this one I indicated the letter M. If you want to use with this eye gaze board ‑‑ you will have a download of this on your resources ‑‑ you first identify the color. This is an orange color. On the outside of the color you have a colored boarder. You first look at the square that has the boarder with the color that you want. So you see the orange boarder is around the square D expensive F and 456. That's not what you are looking at first. First is the color. Once they identify the color that you want, then you go to the square that contains the letter or the number that you want. So we've identified that orange is that and I look at the second square and they say the orange letter and that is M. Your communication partner would then confirm that that is the letter that you wanted and you would indicate that by a yes or no and then you move on to the next letter which they would write down or remember so you can get to the word you're trying to communicate.

So here you see the front of this eye gaze board. This is from the ACE's center in the United Kingdom. You 6 different colors and items. It has an area in the middle that you can cut out and it gives you directions on how to put this together and laminate it. It also has an area on here for space when you finish spelling the word you want, or I made a mistake so that they can back space out the last letter you tried to communicate.

What your communication partner will see is a mirror image of the boards and the numbers that you will be looking at. Here the green square is now on the right-hand side whereas for the person communicating it would have been on your left-hand side and the letters are backwards. This allows your communication partner to see the same thing you're looking at in order to be able to communicate. This also takes a little bit of practice and timing, but it is something that is easily accomplished when you remember that twostep process of first the color and then the number or letter.

After you have decided what communication boards that you want and how you are going to access those communication boards, you want to put all of that together in a paper or letter that gives the staff instructions on how you would like to communicate while you are in this emergency setting.

You want to provide a copy of the instructions with the fact of what your desired communication is. Whether you want to use yes/no questions, whether you want communication boards or spelling boards. Again, that can be a personal preference and it could be all 3 of those. You want to access your communication. Especially if you can't touch the boards yourself. These are low tech strategies to use while communicating but we are keeping this in the low-tech realm because communication in these types of settings needs to be quick and easy for both yourself and the staff or nurses or doctors using it with you.

This is an example of an instruction sheet. If you look over to the left, this is done by toby DynaVox. It is divided up into two sections. The first is the instructions and the bottom is the example of how to do partner assisted scanning if that was the method you chose. You could also write out eye gaze. I highlighted the first part of this. You can change the instructions that are on this template to reflect what you need. In the first one it would say tell the person this is a way for them to communicate while on a ventilator. You want to change that to reflect your information that you want to give to the staff. Tell the staff this is a way for them to communicate with you while on a ventilator or whatever level of respiratory support that you need. So you can customize that to meet your needs. These are the references that I talked about Earlier. All of the boards that I mentioned in here have the name of the board, as well as where those boards can be obtained and the link for them. Almost all of these are at no charge. There is one that there is a minimal charge for it, but you can look at them to decide what boards are going to best meet your needs. So we have two boards of that. If you have any other questions, you can also contact either Liz or myself with the information that you will get at the end of this presentation. So Liz I'm going to turn it over to you to talk about the resources we're putting together. Thank you.

Liz Persaud: Thank you so much DeeDee. Gosh that was such wonderful helpful information. You laid it out so it will be so helpful for so many people including myself so we can build our arsenal of tools for empowerment.

We want to share with you the COVID‑19 resources for people with disabilities. The Tools for Life team, as we mentioned, a lot of our work has been in direct response to COVID‑19 by building resources for the community. This guide is alive and well and is still growing. We're adding resources to it every day. You can find this on the Tools for Life website. I included a screen shot on the left. In the middle it says Tools for Life and COVID‑19. We're posting it on our social media. This has been circulated throughout the country. When you dive deeper into this resource guide you'll find so much information on planning guides and resources, helpful apps, virtual platforms, connectedness, entertainment. One of our webinars in this series is about recreation and entertainment during times of quarantine.

Before I give this microphone to Carolyn to wrap it up and talk to you about reaching out to us, I wanted to stress a couple more points. DeeDee shared such helpful information and resources. I think when it comes to communication, especially if you are not an active AAC user now, practice. Practice makes perfect. Download these resources. Start practicing with your friends and family, those who you are quarantined with at home. Be proactive. Create a plan. Naturally people with disabilities are always thinking outside of the box. We are often two steps ahead. This is the time where we have to be 5 steps ahead. This is the time to come up with the plan now. Document your desires and what you want and don't want. I have a list of the top 10 folks I want to communicate with. Gather your equipment. As DeeDee was saying. We're not sure what hospitals are going to be telling folks about bringing your equipment in. Sanitize it. Label it. Be ready to go. Be proactive now. If you are able now, however you're able to communicate, communicate now. Communicate your wishes, desires and everything you want. Get it laid out and let folks know what it is that you want for yourself. You're going to be the best person to tell people about how to work with you, what your desires are and that's the best thing we can offer now is to practice, create that plan and be proactive. We thank you for joining us. I'm going to give the microphone over to Carolyn Phillips.

Carolyn Phillips: That was outstanding. DeeDee, I so appreciate everything that you're sharing. Excellent information, excellent resources. Liz, that's such great insight. Thank you. To all of you who are listening to this, I want to let you know that we like a lot of folks do better when we have information. I think that it calms fears, it calms a lot of anxiety that can stir up. So we do hope that you got some good information or tips that can help you to get to where you need to go. We are indeed here to help. Feel free to reach out to us. We also want to hear what other technology series, what other thing that you need to know and how we can help. Reach out and let us know. We absolutely are here to serve. You can get in touch with us on multiple ways. You can reach out through our website at AG Tools for Life.gatech.edu or... [Reading from PowerPoint].

So I encourage you to reach out and let us know and know that we are absolutely here in the struggle in the hope with you as we collectively move through this moment together. So stay safe and be well and thanks again to Heather who is doing an outstanding job captioning and thank you to Liz and DeeDee. Take care, everyone.