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>> CAROL DOW-RICHARDS: Perspectives on Aphasia: Communication Breakdowns in Medical Settings. Carol Dow-Richards, aphasia advocate and author. David Dow, stroke survivor and author. John Shultz, MD. And our email is aphasiastupport@gmail.com.

Speaker disclosure for David Dow. Financial, director of cruises and events at the Aphasia Recovery Connection. Co-author of "Healing the Broken Brain: Leading Experts Answer 100 Questions About Stroke Recovery." And "Brain Attack: My Journey of Recovering from Stroke and Aphasia." Financial compensation from ASHA for this presentation. Non-financial, stroke survivor and a resource advocate.

Speaker disclosure for Carol Dow-Richards. Financial, founding Board Member and director of the Aphasia Recovery Connection. Independent contractor at St. Rose Dominican Hospitals, Las Vegas, Nevada. Co-author of "Guide to Living with Aphasia." Financial compensation from ASHA for this presentation. Non-financial, member of Aphasia Access, aphasia advocate and resource advocate.

Speaker disclosure for Dr. John Shultz. Financial, anesthesiologist at Columbus Regional Hospital in North Carolina. Financial compensation from ASHA for this presentation. Non-financial, volunteer and speaker for Aphasia Recovery Connection. Medical team volunteer for Aphasia Cruises.

Welcome to Perspectives on Aphasia. We will be discussing communication breakdowns in medical settings. Aphasia presents big problems for patients. Next, David, a stroke survivor, is going to share a patient's story of a big problem with a simple solution.

>> DAVID DOW: Hi. I'm David Dow. Today I would like to introduce you to my friend, Rob, another stroke survivor. The problem all started on a summer afternoon. Rob, John and I were having a beer. During our visit, Rob discovered he was unable to move his right leg. Fearing he was having another stroke, we dialed 9-1-1.

When we arrived at the ER, we saw the doctor asking Rob questions. The doctor was speaking very fast. He was asking yes or no questions. But he was not checking to see if they were accurate answers.

We asked Rob's permission to offer some help for him. Dr. John explained to the doctor that Rob had aphasia. He suggested the doctors write down keywords. We asked the doctors to slow down.

Next, we wrote out a self-advocacy sheet that included a little about Rob, his aphasia. And we included his wife's cell phone number.

Imagine if you were the patient. Would you want a whiteboard? Would you want the doctors to slow down? Would you feel afraid or insecure if you were not sure what was happening to you?

This is a picture of Rob on the day of his discharge. He sent a photo in a thank you note for making a difference. The takeaway for a therapist and loved one is this, write out a simple self-advocacy sheet for patients. Ask staff to slow down. Have a clipboard or whiteboard for patients.

I have been in Rob's shoes as a patient. I can tell you, it is terrifying to be in a medical crisis and not being able to talk, read or write. I hope this presentation gives you some insight and ideas that will be helpful to people with aphasia in the medical settings.

>> DR. JOHN SCHULTZ: As we have seen with Rob's example, teamwork matters. Doctors, nurses, patients, family members and friends. Next I will share with you information from the Joint Commission and their thoughts about communication or lack thereof. Then David will share his experience of his stroke and aphasia as a patient. And finally, David's mom will share types of resources as a caregiver. As we move through the presentation, we are asking you not only to listen and to learn. We are asking that on behalf of the patients like Rob and like David, we are asking for your commitment to translate ideas into action. That is how we make a true difference.

So grab a pen and paper, if you haven't already. And take the ideas, develop a plan, and act on it.

I am an anesthesiologist and worked at Duke for many years. You might wonder how I know so much about aphasia. I've been an active volunteer on the Aphasia Cruises. Each morning on the ship I have breakfast meetings with the cruisers where we learn from each other. On every cruise I offer a role playing session between doctor and patient and teach those with aphasia how to be better advocates for their own care. I encourage life participation approach to aphasia activities on the ship as we all like to have fun.

Patients who have good communication with doctors are more likely to adhere to treatments and follow advice. This is strongly associated with their recovery. They are less likely to launch complaints or initiate malpractice complaints.

However, many doctors tend to overestimate their ability in communication. In the saying of stroke and aphasia, effective communication between doctors

and patients cannot be assured. In fact, this is the entire purpose of this presentation. Doctors and patients need your help. In meeting over 100 people with aphasia over the past few years, I have heard countless stories of communication breakdowns. I believe these breakdowns are affecting the care of our patients. I believe we need to advocate on behalf of patients with aphasia. And it is difficult for them to self-advocate.

As professionals in charge of their care, we need to ensure their care and safety in the medical setting. Sometimes it is as simple as taking the time to talk to the staff. Or offering information about aphasia by providing or posting ASHA aphasia fact sheets for the fellow staff. Or helping your patient become their own advocate by providing them with their permission a self-advocating sheet like we did for our friend, Rob.

Communication failures are the leading root cause of sentinel events reported to the Joint Commission. More specifically, the Joint Commission cites communication failures as the leading root cause for medical errors, delays in treatment, wrong-site surgeries, and operative and postoperative mal events.

Imagine not being able to read anything in the hospital or not being able to understand what is said in the hospital. Patients often struggle to read or understand spoken language. There's much patient dissatisfaction and many complaints are due to the breakdown in the doctor and patient relationship.

Effective communication really is central in building the staff-patient relationship. I believe that this communication is really the heart and the art of medicine. Next I would like to introduce David Dow. David is a stroke survivor who had a stroke at age 10. He is now 33.

As a patient, David was unable to express himself, his fears, resistance, insecurity. Communication was taken from him. David is an expert on patient care because he was a patient for so long.

At age 10 he could barely say anything. He couldn't spell his own name. His comprehension of auditory information was gone. He was totally paralyzed on the right side. He had global aphasia. And he was hospitalized for three months.

His family was told by one doctor to put him in a nursing home. His family chose to fight for his recovery. And David fought hard, too. He went to speech therapy for 15 years, starting with single words, single letters. Then bigger words and more letters.

Today David is an author. And today he will share his insight from being a patient himself.

>> DAVID DOW: I had a stroke at age 10. I could not understand what was happening to me. I could not talk. I had no tools to support communications. I could not understand what was being said.

I didn't understand simple information. I didn't know if I would improve. My family didn't know how to communicate with me. And my family was not given brochures or resources. There were no aphasia apps in 1995 when my stroke happened.

Next we will look at tools and resources you might want to consider. Your patients rely on you for resources for safety. Are their needs met? For leisure. Are there resources you can offer to them? And remember the family because connection matters. Are there resources to help families? But first let's start with a simple question, what is most important?

We asked Dr. Audrey Holland, aphasia expert that question.

>> DR. AUDREY HOLLAND: First of all, it's very important for people around the person with aphasia to understand that this is a predominant language problem, not a problem in one's ability to think. And I think that one of the problems that many people have with communicating with their now aphasic friends is that they don't have that clear that this is language not thinking.

>> CAROL DOW-RICHARDS: I'm David's mom. I stayed with David in the hospital for three months in 1995. He was only 10 years old and had a diagnosis of global aphasia at that time. We were frustrated. We played a lot of charades. We also cried a lot. We needed help. We needed resources.

I'm going to talk about different types of resources and why they are useful. We have included specific examples of both free and for-pay resources that we have had families share with us and we have personally found them to be useful from our own experience. We are not promoting any specific program, product or service and we don't receive any sort of financial gain related to these resources. What we are promoting strongly is how impactful various types of resources can be, both for professionals and for families dealing with aphasia.

Many families are completely lost when it comes to aphasia. We hope you will find specific resources that work for you and your clients. And share them with colleagues, friends and with your clients.

More than 90% of the families we interviewed said they did not receive any written information on aphasia while in the hospital. David and I spent three months together after his stroke at four different hospitals. Like many, we were not given a handout on aphasia during our stay. That would have been very helpful.

Additionally, families share that they often do not know how to spell aphasia. So they often struggle to search online.

Finally, we cannot assume that all families have access to the Internet. So we have a problem. Let's look at a solution.

Having been a caregiver, I believe that every family should be given basic information in writing about aphasia. Have printouts for families, for the doctors and nurses, and others that are working with your patients. Highlight relevant tips. You might suggest that the patient post information about aphasia in their hospital room.

Give the family extra copies of handouts on aphasia. Next I'm going to share a link to a suggested resource. Prepare to put this link on your phone or tablet for easy access. Let's look at an example of a type of resource available from ASHA.

This is a good example of an educational piece to print out for families, for staff, and for patients. The entire document is three pages. And it is available in both English and in Spanish. This resource is from the American Speech Language Hearing Association. You'll see the link at the bottom of the slide. Take time to save this link or grab the screenshot so you can offer this information to your patients.

While in the hospital, my son, David, was given a wheelchair. That helped bridge his need to move. However, we also needed a bridge to communication. If he was thirsty, there was nothing to point at. What if he wanted the lights off in his hospital room? What if he had to go to the bathroom?

We played a lot of charades all too often. And it left us both very frustrated. Not having access to communication required that I stayed with my son 24/7. Having a communication board might have given us both some piece of mind so that I could have left his side for short periods of time.

This example also shows an alphabet board for patients that can read. Find a board that works for your patient. No two are alike. Many are available online in several languages. Many are available online laminated. Or you could make your own communication board and laminate it. Or put it in a sheet protector for your patient.

Keep in mind these should be for single patient use. And should be able to be wiped clean and sanitized, as needed.

My son, David, was unable to speak. I found that having a whiteboard or a

clipboard with paper handy for drawing was very helpful. Today there are many apps that have whiteboards or alphabet boards. And there are many options on the App Store.

You might suggest for both patients and their families that they download apps to make communication more successful. Or if your families don't have a SmartPhone, suggest a simple clipboard or a whiteboard, as that will be very helpful.

Let's look at apps that can assist with communication in the medical setting, the ER, or in intensive care. Patients need visuals to share their pain levels or their location of pain. Imagine if you were the patient entering the ER and you could not verbalize your emergency needs.

We suggest that you share this type of app with both the patient with aphasia and with staff members who treat them. I have shared this app with the ER staff in my local community. And they are delighted to have the tools. They just need someone to share the tools and resources with them. Perhaps that someone could be you.

Having a pocket card with aphasia information and an ID is important for patients so that they can self-advocate both in and out of the medical setting. I facilitate aphasia support groups in Las Vegas. Many new attendees have no tools to self-advocate so we provide them with an aphasia wallet card.

One of my support group members shared that he was pulled over for speeding. Imagine not being able to speak. Having the aphasia pocket ID card allowed this member to self-advocate and share about his aphasia with the police officer.

I like this particular resource as it is available in both Spanish and English and it can be personalized specific to the needs of your patient. And I like it because it's free. You can search online for an aphasia wallet card that fits your patients' needs.

SmartPhone safety skills are important. 1 in 4 stroke survivors may have another stroke. Knowing how to dial 9-1-1 with aphasia is a critical safety skill. For example, on an iOS phone rapidly clicking the sleep/awake button five times will call 9-1-1. And share the current location. Emergency SOS will notify the emergency contacts with a message that say that this phone has dialed 9-1-1.

Learn this skill on your own phone so that you can share with your patients prior to discharge. Or create a handout for caregivers to assist when your patient is ready to use their SmartPhone again.

Visual tools to explain aphasia to professionals and families can be very useful. If I had aphasia, I know I would appreciate having a visual booklet, such as "What Is Aphasia." This might be a good booklet to share during your sessions with clients as you practice reading, listening, or speaking skills. It is surely interest driven to the patient as they want to understand.

They want to understand their diagnosis. Often explaining it auditorily is not sufficient. Many times people with aphasia need a visual to help them understand. This is one resource we found to be very aphasia friendly. And the aphasia store offers many such resources.

As a caregiver, I believe that families should be referred to support services post discharge. The National Aphasia Association offers links to support groups. We suggest you check for support in your local area or online.

While the families could surely look this information up themselves, I can speak from experience that the time in the hospital is so overwhelming and so stressful that having someone do this step for the patient and their loved one is very appreciated.

Another resource David and I have found very valuable to our own education is Aphasia Access. This is an alliance of life participation approach to aphasia or LPAA providers. They provide resources, networking, and education for professionals specific to the LPAA model. And we believe that this is a critical underpinning of long-term success for people with aphasia.

As we come to a close, David, as a patient, will share some additional tips and reminders. You probably already know them. But the real question is this: Does the family know these tips? Does the hospital staff know them? We need to find ways to share the information to fellow staffers. We need to bridge the communication. And if each of us in the aphasia community, patients, caregivers, therapists, and staff, start to make simple changes, the ripple of tide of change begins.

>> DAVID DOW: Here are some tips and reminders that I think would be very helpful during my hospital stay. No background noise. Draw for me. Give family information on being good communication partners. Give family a handout. Show me apps that I might be able to use. Tell the nurses station that I cannot communicate so I cannot use the call button to speak. Talk to me and look at me when you are talking. Many people with aphasia complain of feeling invisible.

Together we can make a difference in the lives of those dealing with aphasia. Patient safety requires the staff to be effective communicators and support patients across the services of a complex medical system. We can work

to help empower the patients.

What would you add to your toolbox? How can you improve the hospital experiences for patients with aphasia? I hope you have found some ideas for you to practice.

You have listened and you have learned during this presentation. What matters next is your commitment to translate the ideas into action. On behalf of people with aphasia, I ask that together we can create change and improve the status quo. Together we can.

We are all part of a team. Caregivers, patients, doctors, rehab professionals. It takes a village to create change. What resources would you add to your toolbox? Next we will review some of what we covered. Write down three or five action steps you can take to improve the quality of care for people with aphasia.

Create a patient self-advocate sheet for your patient. Download basic information about aphasia, such as ASHA handouts to share with staff and patients. Find apps that can enhance hospital communication between patient and staff. Also, find a whiteboard app for your patients or offer them a clipboard or a communication board to help them out. Print a personalized wallet card for patients so that they can self-advocate both in and out of their hospital stay. And also, help patients find support groups or resources within your area.

I progressed in rehab. Finally, I was able to talk again. Starting with just single words.

Speech and language therapists really helped me. I have years and years of speech therapy and can speak quite well now. I can read and write again. Things aren't as easy as before but I live independently and strive to live a normal life.

On behalf of those with aphasia, thank you.

>> This presentation is part of the upcoming ASHA Online Conference, Improving Functional Outcomes in Aphasia. This comprehensive event explores fundamental practical topics in aphasia intervention as well as other subjects including medical management, neural plasticity, life participation, assessment and more. Sessions address the needs of patients across the severity spectrum and in various treatment settings, as well as the unique needs of a range of patient subgroups. You can learn more at [www.ASHA.org/events/aphasia](http://www.ASHA.org/events/aphasia).

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