



The Missing Link for SLPs Podcast

The Speechless SLP Series

freshslp.com

Episode 104: A Speechless Recovery: What is Post Intensive Care Syndrome?

Post Intensive Care Syndrome, or PICS, may be relatively new as a formal diagnosis, however it is a very real condition patients and/or their family may experience after spending time in ICU. In episode four of The Speechless SLP series, Anna Lewis, Clinical Social Worker, talks about what PICS is and types of care during and after critical illnesses that can help with recovery. Vanessa Abraham speaks about dealing with her symptoms after her time in ICU, and the benefits of her participation in a PICS support group.

Discussion & Reflection Questions

1. How might the different approaches of an interdisciplinary team help your clients/patients?
2. If your patients/clients may not be able to cognitively process treatment at the time, is there a way you can document their care to give to them and/or their families to help them understand later?
3. How would your clients/patients' quality of life benefit from various forms of palliative care as part of their treatment?

Quote from the Conversation

"For patients with PICS, my best advice is find your community. Find your people that are going to remind you that you're not alone. For family members, believe your loved one about what they're experiencing, and when they say that it's real, it's real."

- Anna Lewis

Anna Lewis, MSW, LCSW



Anna Lewis (she/her) is a PhD student in the Department of Health Policy and Management at the University of Pittsburgh Graduate School of Public Health. As a graduate student researcher, Anna's work focuses on Medicaid beneficiaries and the effects of permanent supportive housing.

Prior to returning to graduate school, Anna worked as a senior social worker at the Critical Illness Recovery Center at UPMC Mercy, one of the most comprehensive outpatient follow-up clinics for survivors of prolonged intensive care unit stays in the nation. Anna also worked as an inpatient palliative care social worker for several years. Anna received her Bachelor of Science in Human Development and Family Studies from The Pennsylvania State University in 2010. She attained her Master of Social Work degree with a certificate in mental health in 2012 from the University of Pittsburgh, and she is also a licensed clinical social worker.

Anna lives in Pittsburgh with her husband Sean, five-year-old son Sam, and dog Nittany.

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**Vanessa Abraham,
MS, CCC-SLP**



Vanessa is a wife, mother and school based Speech-Language Pathologist.

She learned firsthand what it's like to be on the receiving end of speech services after experiencing a sudden-onset critical illness that left her with

limb and neck paralysis as well as a PEG tube and tracheostomy. She was thrown into the rehabilitation world after being an independent, healthy and vibrant young mother. Through many swallow studies, voice therapy, OT and PT, she had to learn to eat, talk and move again.

Her goal now is to help people critically ill patients cope with the grief they experience after a critical illness through speaking up about the topic of Post Intensive Care Syndrome (PICS), depression and anxiety post ICU in addition to educating families and patients about the various rehab modalities that have been successful for her.

Contact Vanessa Abraham
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Quote from the Conversation

"You need to be able to heal your mind to heal your body. Your head needs to be in the right place. I've done so many things for mental health. But the PICS group, being around other PICS survivors, hearing their stories, has helped me more than anything. Just knowing that I'm not alone. It makes me feel whole again. It makes me feel normal, in a way."

- Vanessa Abraham

**Mattie Murrey Tegels,
MA, CCC-SLP, L, CPC, CLSC**

*Medical Speech-Language Pathologist and
Founder of Fresh SLP & Badass SLP*



Mattie Murrey-Tegels is the founder and SLP behind Fresh SLP, Badass SLP, and The Missing Link for SLPs Podcast. She's been "in-the-trenches" as a medical SLP around the world for over 25 years and now an Assistant Professor for 3 years. She is thrilled to be adding this dream of a podcast

because paying her experiences forward is something she is very passionate about. If you ask her patients and students, one thing they will remember is how much she loves her job!

She may not look like it but she is a huge introvert and when she is not actively working as an SLP, she is almost always reading, writing (writing over 1,000,000 words a year), or listening to amazing Chicago Blues bands. She also loves being outdoors and definitely enjoys soaking up the sun at her home in Minnesota, where warm and sunny days can be limited. She's ridden motorcycles for many years, raced sled dogs, hiked huge mountains yet she cherishes the quiet moments of climbing into a hammock to nap or timeless conversations with friends and family. The Missing Link for SLPs podcast and Fresh SLP is her legacy, giving back to a career that has so richly rewarded her.

Quote from the Conversation

"One of the reasons why I do this podcast is to learn about approaches like this, in teams like this, and work that other people are doing that we can share and learn and integrate."

- Mattie Murrey-Tegels

Keep the Conversation Going

Do you want to know more about Post Intensive Care Syndrome (PICs)? Below are some of the organizations and groups Anna recommended in this podcast.

The Society of Critical Care Medicine

<https://www.sccm.org/MyICUCare/THRIVE/Post-intensive-Care-Syndrome>

The Critical and Acute Illness Recovery Organization (CAIRO)

<https://sites.google.com/umich.edu/cairo/about-us>

CAIRO on Twitter @CAIROrg

<https://twitter.com/caiorg>

Thank you for listening to *The Missing Link for SLPs* podcast! **If you enjoyed the show, I'd love you to subscribe, rate it and leave a short review.** Also, please share an episode with a friend.

Together we can raise awareness and help more SLPs find and connect those missing links to help them feel confident in their patient care every step of the way.

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or learn more at FreshSLP.com or badassslp.com.

Let's make those connections. You got this!

*Do you have a question you'd like answered on the show?
Interested in sharing your experience as an SLP with our audience?
Send a message to Mattie@FreshSLP.com!*

Not a substitute for a formal SLP education or medical advice for patients/caregivers

The Missing Link for SLPs Podcast Show Notes

Post Intensive Care Syndrome, or PICS, may be relatively new as a formal diagnosis, however it is a very real condition patients and/or their family may experience after spending time in ICU.

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The Missing Link for SLPs Podcast Full Transcript

Mattie Murrey 00:05

Hi, everyone, and welcome to the Missing Link for SLPs podcast. I'm Mattie, your host, speaker, and very passionate speech language pathology advocate. You are listening to The Speechless SLP series with Vanessa Abraham, and you get a unique perspective in each one of these episodes on her journey being the speechless SLP in the ICU bed, unable to talk. So, welcome to this series of the Missing Link for SLPs podcast. Glad you are here. Sit back, take a listen.

Welcome back to the Missing Link for SLPs podcast. We are continuing on with our Speechless series with Vanessa Abraham, and we have another guest with us today, Anna Lewis. Anna Lewis is not an SLP, but she is one of our best friends that I am excited to learn about, and you're going to hear why in just a minute. Anna, welcome to the program, and Vanessa, welcome.

Anna Lewis 01:02

Thanks so much for having me.

Vanessa Abraham 1:02

Hey.

Mattie Murrey 01:03

It's always that first like welcome, and everybody's like who speaks first, right? So, we're excited you guys are both here. And when Vanessa and I were pulling together how and who we wanted on this series, she said, you have to meet Anna Lewis. Anna Lewis, you are who?

Anna Lewis 01:23

So, I am a licensed clinical social worker, and I have been in the medical field for about six years, and currently, I am a PhD student full time.

But prior to that, I worked as the social worker for a place called the Critical Illness Recovery Center at UPMC, Mercy in Pittsburgh. So, it's a fairly unique clinic, there aren't very many of them around. And what the clinic is, is it sees survivors of critical illness who have spent extended periods in the ICU. So, they have all sorts of symptoms. and things going on that we are seeking to try and help them with.

And so, that was my life before my PhD program, and now I am doing research in that area too, in ICU survivorship and what that looks like for folks coming out, because it's not just you come out of the ICU, and you're all better –

Mattie Murrey 02:24

Right.

Anna Lewis 02:25

– like TV shows make it look like! So, this is not TV medicine or movie medicine. This is real life. And so, a lot of folks struggle, and we're trying to help with that struggle.

Mattie Murrey 02:37

Vanessa, this has been something near and dear to you, right?

Vanessa Abraham 02:42

Absolutely. The concept of Post Intensive Care Syndrome was definitely not one that was discussed in grad school, and I had the unfortunate opportunity to learn what it's all about just through my journey. I really didn't know what it was that I was experiencing until somebody brought it to my attention, and that's when Anna came into my life.

Mattie Murrey 03:03

Not something you learned in grad school?

Vanessa Abraham 03:04

Absolutely not. There's no class on PICS. There's not a chapter in a textbook on PICS. It's definitely something that's not talked about. Even the professionals treating me at the time didn't have any clue what was going on. They didn't know what that was. Even today, I still talk to professionals in the medical field, and they're very unaware of what PICS stands for, what it looks like.

Mattie Murrey 03:34

Is it something that's well known in your field, Anna?

Anna Lewis 03:37

No, it's not, I wouldn't say that PICS is well known in social work. It's certainly not something that we learned about in graduate school either. I was in the medical field for several years before I even heard



the term. Now, to be fair, it wasn't really given a name until the early 2010s. So, it's only been PICS, it's only had a name since – I think it was around 2012 when they actually named it as a condition. But it's been observed for far longer than that, obviously.

Mattie Murrey 04:10

Mhm.

Anna Lewis 04:11

But I did not receive any formal training in it in graduate school. It wasn't until I was in the field and seeing patients. Actually, before I came to the clinic, I worked with the palliative care team. So, we were often working hand in hand with the ICU team for a lot of different reasons for folks. And we had patients that we would follow outpatient for palliative care as well. And we would see these signs and symptoms, and that's sort of how I was exposed to PICS.

And I was around when Mercy Hospital was founding the clinic here. And so, that clinic was founded here in 2018. So, we've been seeing patients there since 2018. There were several other clinics around the country that started a little bit sooner than that, but because it's still such a newly developing field, there is not a lot of education out there on PICS for people coming through professionally.

Mattie Murrey 05:09

So, for those listeners not familiar with palliative care, what is palliative care?

Anna Lewis 05:14

So, palliative care is a specialty service that is meant to focus on enhancing an individual's quality of life when they have some sort of life limiting illness. So, it's not the same as hospice. Hospice can be a form of palliative care, but that's sort of reserved for individuals who are in the end stages of whatever disease process they might have. Palliative care can be at any point in the disease process. And even for folks who are seeking curative treatment, it's more about looking at the person as a whole person, and making their journey as comfortable and manageable and high quality as it can be throughout the course of that illness.

So, we can start right at the beginning as someone is starting their treatment for whatever disease process it might be, and help manage some of the side effects of medication that they're having. Or work on things like energy conservation, and making sure that they are going to still be able to play with their kids when they're going through these treatments. Or we work with individuals who are further along in the process and may be shifting – thinking about shifting their goals to exclusive focus on comfort. So, palliative care works really hand in hand with our ICU teams, for sure.

Mattie Murrey 06:31

I have so many questions. Vanessa –. Oh, one more quick for you, Anna. Do speech pathologists work with you in the PICS program?

Anna Lewis 06:43

Yes. So, our clinic is one of the most comprehensive in the country. I would like to say it's the most comprehensive. It's at least one of the most comprehensive. Our team includes a physician, or the critical care intensivist, a nurse practitioner, a social worker, a speech language pathologist, an occupational therapist, a physical therapist, a pharmacist, a respiratory therapist, and a dietitian. So, our team, and every patient that comes, sees all of those people! So, it's a very lengthy visit –

Mattie Murrey 07:17

Oh, a team!

Anna Lewis 07:18

– but they get a huge amount of information about – it's sort of that one stop shop, where they just get a huge amount of information about how they are doing when they come to our clinics. So, it's intensive, but it's a very wraparound sort of service.

Mattie Murrey 07:36

Like a concierge approach.

Anna Lewis 07:37

Absolutely. Yes.

Mattie Murrey 07:39

This gives me goosebumps, because one of the reasons why I do this podcast is to learn about approaches like this, in teams like this, and work that other people are doing that we can share and learn and integrate.

Vanessa, I know you have said this has just been key, and I've been so impressed by the team members that you've worked with on your road to recovery. This one has been pretty important for you.

Vanessa Abraham 08:06

Yes, this has probably been one of the best. So, let me backup a little bit. Anna runs a weekly group, virtually. She's back east. I'm on the west coast. So, it's a virtual meeting that we have every week. And I think I've said in my previous podcast, I've done so many things for mental health. I've done hypnosis. I've done EMDR. I've done – just cognitive behavioral therapy. But her group and being around other PICS survivors, for me, and hearing their stories, I would say has helped me more than anything. Just knowing that I'm not alone. There's so many people during my day that I communicate with that really truly they care, they love me, and so on, but they don't really understand and being around other ICU survivors just – it makes me feel whole again. It makes me feel normal, in a way.

Mattie Murrey 09:14



And not so siloed, isolated.

Vanessa Abraham 9:17

Yes. Not alone in this journey.

Mattie Murrey 09:20

What was one of your biggest questions when you first started working with Anna?

Vanessa Abraham 09:24

Gosh, that's a good question. Gosh, every week I feel like I have a question for her. Every week. Topics change. I don't know if there was one specific question. There were a million, and there still are.

Mattie Murrey 09:36

A very dynamic process, then.

Vanessa Abraham 09:39

Yes, every week it changes. And honestly, every week that we do talk, it opens up a whole other can of worms, for me. Other topics, other thoughts that come through my mind of, "Oh, how can I deal with this?" "How can I..." For example, "How do I deal with anniversary dates? How do I deal with the PTSD associated with an anniversary date? How do I deal with the mental load of going back to work?" Every week there's something.

Mattie Murrie 10:06

Mhm.

Vanessa Abraham 10:07

Like, for example, the topic this week is going to be different than last week, and I know the topic this week is going to open a can of worms in my head, thinking, "Oh, well, yeah. What about this? Or what about that? Or I've experienced this, or I've experienced that. How can I improve in that area?" So, to say that there's one thing, I think there's a million for me.

Mattie Murrey 10:28

So, a million cans of worms –

Vanessa Abraham 10:30

Yes.

Anna Lewis 10:30



- can be translated into a lot of opportunities to unpack the body, mind, heart correlation, and address all that you've been through for really comprehensive healing and movement forward.

Vanessa Abraham 10:45

Mhm. Absolutely.

Mattie Murrey 10:48

Topics. I didn't know the meetings were topic driven. Anna, can you share with us some of the topics?

Anna Lewis 10:53

Absolutely. So, the topics really come from the conversations that we have. So, we - initially, the group started out as an in-person group here at Mercy. It was for our clinic patients only. And then March of 2020 hit, and that was no longer a feasible way to function for our support group. And we came together as a team and said with the pandemic happening, we need to make sure that we are providing as much support as we possibly can, and monthly is not going to cut it. When everyone is feeling so isolated, that's just not going to be enough anymore. So, we said, what if we went to weekly? What if we did weekly virtual meetings? That would open up our ability to care for people who are not just our Mercy hospital patients. It would also open up the opportunity for people who cannot travel to be anywhere. We can't gather in groups. So, let's just sort of - let's open this up a little bit, and see what happens. And through that, we were able to connect with some other clinics. The clinic that Vanessa goes to over on the west coast, reached out to us and said, "Hey, we have some patients that we would really like to refer to your support group because we don't have one". We had several other clinics do the same thing.

And so, leading the group, I always say, "The group is not for me". Like, if we never get to the topic that I brought for the day because the group needs something else, that's great. We'll shelve the topic, and we'll talk about it next week. But we do a lot of different topics. So, this week, we're talking about guided imagery. We do some CBT techniques where we do challenging some negative thoughts that we're having. We have talked about how to talk to your family about all of this, and how to help them understand what you're walking through. We've talked about acceptance. Setting goals. We've talked about - oh, man - we talked about anniversaries recently when that was something that came up in conversation.

So, I try and listen to what's being said in the group, and hear sort of the undercurrents of topics that are being talked about, but not directly talked about. And that's kind of how I pick what we're going to talk about next because that says to me, okay, this is a topic that would be really good for the whole group, because I'm hearing this person sort of mentioned it, and that person sort of mentioned it. So, let's bring that to the forefront as part of the conversation.

So, we've done all sorts. We had a pet therapist come one time, and talk about pet therapy. We invite all of our clinic providers. So, since we have such a comprehensive clinic, we've invited all of them to come at various times, and be like guest presenters. So, they've done stuff like energy conservation. Our wonderful occupational therapist has talked about energy conservation. Our speech language pathologists have come and talked about making task lists to help you with your cognitive functioning,



and how can we help cognitive function improve in PICS – individuals who have pics. We've had our physical therapists come and talk. We've had everybody come in and sort of lend their expertise.

And it's one of my favorite parts of the clinic, is that group, because I do think it has one of the most direct impacts on people not feeling so isolated, and not feeling like "I thought it was just me", and not feeling like "I thought I was going crazy".

Mattie Murrie 14:30

Mhm.

Anna Lewis 14:31

We've had people say that, "I thought I was going crazy because of all these things that I was experiencing". And coming and hearing other individuals say, "I've been where you are, and I went through that process too. And I remember feeling like that, and it doesn't last forever, and it can improve, and this – where you are today isn't where you're going to be a year from now". I think that has one of the most profound impacts on the patients that we see.

Mattie Murrey 14:59

So, a sense of community, a sense of learning?

Anna Lewis 15:04

Mhm.

Mattie Murrey 15:05

And a sense of hope?

Anna Lewis 015:06

Absolutely.

Mattie Murrey 15:07

Is it for the individuals themselves? Or is there a family group?

Anna Lewis 15:15

So, our group has never gotten large enough that it has needed to split. We have invited family members. So, family members and caregivers are always welcome to come to our group as well. They tend to not stay as long as in the group.

Mattie Murrey 15:29

Mhm.



Anna Lewis 15:30

So, we have some individuals who've been in the group since the start, and have stayed for the three years that it's been going on – two years since we went fully virtual. But family caregivers tend to not stay in the group quite as long because they don't connect in the same way as the survivors themselves.

Mattie Murrey 15:48

Right.

Anna Lewis 15:48

But family members give great feedback that, "This was helpful in helping me to understand my family member. I'm hearing from other people the same stuff that my family member is saying. And so, I get it more than I did before". So, we don't have a specific dedicated family group, but family members are always welcome to come to our group.

Mattie Murrey 16:07

So, Vanessa, on a scale of one to four, with four being super important and one being not important at all, how important would you say PICS has been for you?

Vanessa Abraham 16:19

Oh, absolutely a number four, no doubt. You need to be able to heal your mind to heal your body. Your head needs to be in the right place.

Mattie Murrey 16:28

Mhm.

Vanessa Abraham 16:29

If you're dealing with chronic depression, anxiety, not wanting to get out of bed, feeling alone – all those horrible thoughts that go along with a hospital critical illness ICU stay, you're not going to recover, if you would, if your head was in the right place.

And for me personally, being around a group of people and talking it out, having people understand me, has made a world of difference. I find with myself, when I hang up from my Zoom meeting with Anna during the week, that my attitude and my willingness to want to get out of bed is so much better, just because I know I'm not alone.

Mattie Murrey 17:17

So, kudos to you for reaching out and being brave. So many people, I think, just turn those emotions off, and say that's a part of my life I'm done with. I'm through it. I'm surviving. Yet, you said this is a resource, and I'm going to step into this.



What did it feel like being that vulnerable, knowing you were looking for something somewhere? Can you share with us some of the thoughts and feelings you had before your first session with joining PICS, and then the relief you felt?

Vanessa Abraham 17:54

I think what the person that originally referred me – it was really strange how it all kind of came out, but she referred me, and at first I was thinking, “Really? Really? This is me? This is my profile now? That I’m an individual that she’s recommending go and seek counseling for this thing called Post Intensive Care Syndrome? What? I have PTSD? You’re telling me I have PTSD? No, this can’t be. No, no, no.” It’s kind of denial, in a way. And then, I went to the first meeting, the second meeting, and then the 10th and 20th meeting, and I realized, “Yeah. This truly is me. And not only that, but this is really helping me”.

I was also doing so many other treatments, like I said, EMDR and hypnosis, just so many things. And I never walked out of those treatments the same way I do walking out of our weekly sessions with Anna, where I’m around other people that are struggling with the same mental issues, and the depression that I have been going through. So, that was just key for me, and I’m so grateful that they did refer me, and they did introduce me –

Mattie Murrey 19:16

Yeah.

Vanessa Abraham 19:16

– to the topic of PICS. Because I really don’t know where I’d be without the conversations that we’ve had in the past, I don’t know, two years or so, since I’ve been attending Anna’s sessions every week. And I did notice, I took a few months off, maybe it was more than a few months because I was – the times of the meetings were times that I had either things with doctor’s appointments, or whatever, life. And I noticed during that time frame, that mentally I slipped back.

Mattie Murrey 19:47

Mhm.

Vanessa Abraham 19:48

I told you this too, Anna, when I came back a month ago, I was like, “I needed to start coming back to these again. This was good for me. This is a good place for me. I need to put this back on my calendar, and make sure this time is open so I can be available”. Because I needed it, and everyone around me needed me to go to it.

Mattie Murrey 20:07

Mhm. Wonderful. Thanks for sharing. You’ve mentioned something before about ICU diaries. I’m not sure who would be the one to ask that question, direct that question to? [crosstalk]



Vanessa Abraham 20:18

I'm going to let Anna talk about that, because she's the one that [crosstalk] –

Mattie Murrey 20:23

She's nodding her head, everybody who's listening to the podcast. Anna's just nodding her head. All right, Anna, take it away.

Anna Lewis 20:30

Yeah. So, the ICU diary project was something that we did here that is a tool for ICU survivors in processing what happens during their ICU journey. So, so many people who spend time in the ICU have delirium, lose track of time, lose days, like actually lose memory of the time that they were there, and mix things up. So, that's a hard part of being in the ICU is it doesn't really give you good logical thought about what that experience was like.

So, the ICU diary is a physical diary. It's a physical journal that can stay with the patient in the room. And it's not necessarily for the patient. They can certainly write in it if they are alert and want to. It's more for the team to be able – so, the team in the family to be able to record this is what happened this day. The nurse might write “This day your family came and visited for this much time, or we washed your hair and braided it, we painted your nails, you were doing a little bit better and could interact with me a little bit more today”. And it gives that chronological sense of what actually happened to the person. So, when they are a little ways down the road, and they're out of the ICU and in their recovery process, they can look back and piece their memories together, put that together.

We had a patient one time who said, “I thought that I was boxing people, I thought that I was a boxer. I thought I had boxing gloves on, and I was boxing against people”. And it was because they were in mitt restraints. And so, they had these mitts on their hands, and they thought they were boxing gloves. And they were able to look back in their ICU diary, and their nurse had written about that. It was like “You were trying to pull your tubes and lines out, and we didn't want to but we had to put these mitts on you so that you didn't pull your tubes out”.

And so, they were able to sort of make sense of some of the delirium that they had, and it takes away some of that power of making it so scary of a memory when you can add back in the truth of what was going on. So, it sort of helps people to get some of that logic back in their story, and some of that timeframe back in their story.

We also included, for folks, pictures of what the ICU rooms look like, because a lot of times they don't actually remember the physical space so well. We put in descriptions of all the different team members so that they'll know who they saw. That's also helpful for family members. As they're there, they can look and see – all of the machines, we have pictures of some of the machines that they might be on, and descriptions of what they are and what they do.

So, it adds back in some of that information that gets lost for people as they're going through the experience to help them process it down the road.



Mattie Murrey 23:35

Amazing. When Vanessa first told me about ICU diaries, I thought, well, this is something that – of course, it's a diary. It's something I would write as the patient, right?

Anna Lewis 23:43

Mhm.

Mattie Murrey 23:44

What an outside of the box way of thinking. Because we don't know what the – when I walk into an intensive care room as a speech language pathologist, I don't know what that patient is thinking, and where their distorted reality might be.

Anna Lewis 24:00

Mhm.

Mattie Murrey 24:01

So, I love the ICU diaries, because it really fills in the blanks. So, then the person can go back and make their own connections.

Anna Lewis 24:08

Yeah. Yes. They can go back and make sense of what happened to them, and in – outside of whatever delirium they might have been having, or if they were even – they might have been aware and hearing, but not able to open their eyes. Or for whatever reason, they may not have had all of their sensory awareness. And so, that can help fill back in those logical pieces, and make sense of that story for them.

Mattie Murrey 24:36

Any HIPAA restrictions or anything with that? How did the staff respond to the ICU diaries? Do they see it as an extra task?

Anna Lewis 24:45

So, it's a little tough to get some buy-in at first, because they do see it as an extra task. When you're an ICU nurse, or you're the doctor taking care of a patient, sitting down and taking the time to write a note about that patient can feel onerous, or like something that you could maybe skip that day, "I'm not going to worry about this today". But when they saw the effects for people after, that was really valuable. They got the feedback about how valuable those patients found it to be, when they were able to process after the fact. And they said, "Okay we see the point in this. It's not just another task for me to do. There's a real reason, and it can be really beneficial for these patients down the line. So, all right. We see the value, so we'll go for it".



Mattie Murrey 25:34

Excellent. Maybe having them come back and be guest speakers! Like Vanessa can go back and say this is what the ICU diary did for me.

Anna Lewis 25:44

Yeah. Yeah, absolutely.

Mattie Murrey 25:47

[crosstalk]

Vanessa Abraham 25:47

I was very fortunate that Dr Rosen gave me a notepad. Well, he told my husband to get me a notepad, and I journaled on my own.

Mattie Murrey 25:56

Mhm.

Vanessa Abraham 25:57

But I was cognitively aware, and I was not heavily sedated. So, I have a lot of things written down. But I remember speaking with Anna about this, probably within the past year, and thinking, what a brilliant idea.

Mattie Murrey 26:10

Mhm.

Vanessa Abraham 16:11

Having information in this diary as to what a tracheostomy is. What's a PEG tube? What do these processes and procedures look like? Just to some parents, and loved ones, and spouses, can refer to this and know what their loved ones are going through. I wish my mom had had that. I remember she was so confused and trying to go to Doctor Google and figure out what these procedures are.

Mattie Murrey 26:42

Mhm.

Vanessa Abraham 26:43

So many people are confused at what a speech pathologist does. Why is a speech pathologist taking me to radiology? And why are we doing a swallow study with a speech pathologist? What does a speech pathologist work on? A lot of people just think "speech"?



Mattie Murrey 26:58

Mhm.

Vanessa Abraham 26:59

What's a nephrologist? There's so many. Especially in my care, I had teams of doctors, and at the time, I didn't know what they were all doing. They just had these fancy names on their badges.

So, to have all of this information in a diary that the loved one can just go to and flip through, and look and see, okay, this doctor is looking at this, this doctor is looking at that. This is what that procedure is going to do. Just in one place would be really, really a nice feature for families.

Mattie Murrey 27:30

So, patient friendly terms, is that currently part of the ICU diary?

Anna Lewis 27:35

Yes. So, all of our materials are at a fourth grade reading level. So, it is as friendly as possible for individuals when they go through and read. So, it's very simple terms. It's plain terms.

Mattie Murrey 27:49

Mhm.

Anna Lewis 27:50

And we also try and make sure that we put in anything that makes noise in the ICU! So, like anything that's going to make noise, makes it in the diary as well. Like this is what noises you might hear, and what it means. Because the alarm bells and everything going off can be so frightening for patients and families. So, that's another thing that we always try and make sure that we have in the diary, is like if it makes noise, we want it in there so that families and patients aren't panicking when "There's air in an IV line, and the IV pump won't stop beeping, is that is that a bad thing? Do I need to call the doctor?" That sort of thing can be really helpful for families to just know, "No, this is just your nurse needs to come in and push a button and everything will be okay!"

Mattie Murrey 28:36

Right, right. And for the patient to know.

Anna Lewis 28:38

Exactly.

Mattie Murrey 28:39



Family members can share. Because I know that sometimes in the middle of the night I wake up with worries and I go back to sleep, and then I get up the next day. I get up, and get up and out of my bed, and I go target those worries.

Anna Lewis 28:50

Mhm.

Mattie Murrey 28:51

But for patients like Vanessa, who is stuck, she's locked in. She can go anywhere except to lay there and worry. And so, to be able to have some of those questions answered. For her to be able to journal is another important thing, and have a resource where she can start getting her questions answered.

Anna Lewis 29:10

Mhm. Exactly.

Mattie Murrey 29:11

So important. We are coming down to the end of our time.

How can people become more involved in PICS? Is there a website? Can we order materials? Can we start our own PICS? How does all of that work?

Anna Lewis 29:25

Yeah. So, there is a website. The Society of Critical Care Medicine has a great breakdown of what PICS is, and the PICS family is, because that's something that we kind of didn't talk too much about today. The PICS family is sort of a subset of PICS, where family caregivers can develop anxiety, depression, PTSD, as a result of their loved one's ICU stay. So, the Society of Critical Care Medicine website has a great section about that. It breaks down everything about what PICS is. What people might experience when they're going through it. What family members can expect, and how they can sort of support their loved ones.

There are also online support groups like ours. There are message boards. The Mayo Clinic does a message board about PICS. So, it's sort of an online support group community, but it's not like a specific time where you have to go. There are also pages on Facebook. One of our group members loves to use – there's a Post Intensive Care Syndrome Facebook group that she is a member of, and she's talked about how that has been really helpful for her. So, there are things out there for people who want to learn more about PICS.

And there's also a really phenomenal organization that is dedicated to combating PICS in whatever way they can called The Critical and Acute Illness Recovery Organization. That's a mouthful. So, they just call it CAIRO. So, CAIRO is a collaborative of all of the clinics like ours, internationally, that want to participate can come and participate. And we come together and share best practices for the clinic, and also for the support groups. So, we come together, and kind of problem solve together, and support one another, and

try and make sure that we are supporting patients as best we can. So, CAIRO is another great resource. They have a Twitter page. They have a website. And that's another great place to get information.

Mattie Murrey 31:19

Well, this podcast does a full show note. So, we will – when you return your guest information, please put those links and resources in there and we will include those in the show notes. So, anybody who's listening to this, go click on the show notes. Very ADA friendly. Everything, the whole transcript is out there, and then there's a section at the end where it's “carry this conversation further”. And that's where we can put some of those links for people who are interested in that.

Anna Lewis 31:47

Great. I will definitely do that.

Mattie Murrey 31:48

Final last words from you, Anna? Final advice for patients?

Anna Lewis 31:56

So, for patients, my best advice is find your community. Find your people that are going to remind you that you're not alone. Groups like this are out there. Groups like you. Like the group that I facilitate that we have here, they're out there. And if you can't find a group, or a group setting is not really for you, find your clinic. Find your team that's going to really wrap around you and make sure that they support you the best that they can.

For family members, I would say, number one, believe them. Believe your loved one about what they're experiencing, and when they say that it's real, it's real. So, please believe them. The other thing that I would say is to be their fiercest advocate. Be the friendly thorn in the side when they're in the hospital and you think something is not right. Advocate for them. And before you try and problem solve for them, ask them if that's what they want, or they just want to hear “I'm here for you, and that sucks. And I'm going to stay here with you, even though it sucks”. So, before you start jumping in and trying to fix it, sometimes that's all that people need, is just the empathy.

Mattie Murrey 33:21

Mhm.

Anna Lewis 33:22

So, believe them is number one, though. That's our like monitor in the clinic. We believe you. We believe you, even if the tests don't show it, even if you're even if your MoCA is totally normal and you're telling us you're having cognitive issues, we believe you. We don't believe the test. So, believing people is the first part.

Mattie Murrey 33:42



Excellent. Vanessa, final words?

Anna Lewis 33:45

Yeah, my MoCA was normal too!

I'm just sitting here in agreement 100 percent with everything Anna's saying. Just everything from believing them, being their support system, advocating for them.

Finding your group, finding your community, that is huge. Some of my closest people in my life now are people that have been down a journey. Not necessarily like mine, but have a story –

Mattie Murrey 34:16

Mhm.

Vanessa Abraham 24:16

– have experienced something in their life that has led them down a new path – a critical illness, something tragic, something profound that's happened in their life. And those people are the people that I know resonate with. And having that tribe and that community has been so helpful for me, and that's why I think Anna's group that she holds every week has been so helpful for me because those are my people. So, that's helped me per se.

For caregivers, I would say everything that Anna said. Support them, believe them, fight for them. Attend counseling yourself. Attend counseling with your loved one so you can talk about these topics together, bring those to the table. Attend some PICS classes or courses with them just to try to understand what they're going through. Be patient too, it's a long journey. It's a long, hard journey. But being patient as another one. So, I think that's about it.

Mattie Murrey 35:28

And PICS provides the hope, and the resources, and the community for people who are recovering from post intensive care.

Vanessa Murrey 35:37

Absolutely.

Anna Lewis 35:57

Mhm.

Mattie Murrey 35:38

Well, thank you both, very much, for coming on today.



Anna Lewis 35:41

Thanks for having me.

Vanessa Abraham 35:43

Yes. Thank you so much, Anna. Thank you for helping me, and being on this podcast. And thank you to you Mattie as well for having us. This has been a great topic to talk about.

Mattie Murrey 35:55

Mhm. I know you were excited about it – very excited about it! Just wait until you meet Anna!

Vanessa Abraham 36:00

I'm very passionate about this topic.

Mattie Murrey 36:03

As you should be. Excellent. Yeah, I love this podcast making a difference. Thanks.

So, hey, SLPs, that concludes this episode of the Missing Link for SLPs podcast. Please visit my website at freshslp.com. Follow me on [Instagram](#), or [jump on Facebook](#) to connect in our safe and friendly Fresh SLP community where we are empowering new and transitioning SLPs. If you found value in this episode, or in any way had an aha moment, or I gave you a fresh perspective, please show me some SLP love, and support me on [iTunes or the Apple podcast](#) app or subscribe to me on [YouTube](#). You got this!

