Genia: Welcome to this COVID-19 edition of the Good Things in Life podcast. I'm really excited to be here today. Sara, Amie and I recorded this interview late last night, way past my bedtime to be honest. And I just kind of want to just sympathize with everybody who's kids are kind of going back to school and trying to do remote schooling and all the teachers and the parents trying to deal with a whole new tech world. So Sara, Amie and I all run podcasts. We have at least some degree of tech capacity and only two out of three of our voices were recorded last night. So we are back today to record this episode. Sara is a registered nurse since 2007 and she obtained her Master's of Nursing in 2009. Her expertise is in maternal child health with clinical experience in obstetrics and in the neonatal ICU.

Genia: She's worked in both academic and community hospitals and home health as a bedside nurse and educator and advanced practice nurse and a professional practice specialist. And Amie is an advanced practice nurse who has over 10 years of experience in women and child's health as well. She's completed her Master's degree at U of T, the University of Toronto, in clinical nursing and also completed a collaborative program with the school of Dalai Lama in women's health. She has numerous role, has had numerous roles in leadership education and is currently working as a quality and safety patient specialist in the risk and quality improvement departments in the hospital in her community. And Sara and Amie are the nurses behind The Gritty Nurse Podcast. And I'm so grateful to both of you for joining me last night and today for this very special episode of Good Things in Life podcast around family presence and safety in hospital. So thanks so much.

Sara: Thank you. I feel so excited to be here today. I feel like last night was our icebreaker and now we're really going to just get into it today.

Genia: That's right. That's right. So you know, I've really in our correspondence and last night had really tried to make it really clear that I recognize how sensitive this is to be, this time is aroundjust how high the emotions are, how difficult it is for healthcare providers and for families to be navigating this time with all of the difficult restrictions in the increased level of risk in hospital. So I think it's great actually that we have the second you know, the second wave at this podcast as well because if nothing else, we're, you know, just we've had that time to go through and go over everything. So I'm going to start right back at up at the top and ask you both how family presence in the hospital helps improve patient safety.

Sara: Well, maybe I can start first and just talk about my time as a bedside nurse, particularly in the neonatal intensive care unit. We know that from my personal experience as well as research that family presence at the bedside, it really improves patient outcomes in all areas. So we know that you are with your child all the time as much as you can be. You are the best person to know your child, even if their child is only, you know, two weeks old, two months old, two years old, it doesn't matter. You are your child's strongest advocate. And what I did see from personal experiences is that parents could often spot things like medication errors. They could sound the alarm when they felt their child wasn't behaving normally. And this is something that is sort of your gut feeling or intuition, something that maybe a nurse or doctor would not pick up on.

Sara: So, even in terms of weight gain decreased infection rate lower readmission rate. I feel like as a, as a parent, you are really that person that is the best advocate for your child. And being in the NICU, we often wanted to have parents at the bedside as much as possible so they could really be confident and learn about the care that they would need to provide when their child was eventually going to be discharged home. So it only makes sense that family presence is something that we put as a high priority.

Amie: Yeah. And just to kind of tag along with what Sara was saying many organizations are moving towards understanding that the patient voice and the patient perspective is an invaluable asset to hospital systems. And how we've seen that is that voice really shares what that, what patient safety actually can look like. So understanding that that perspective is really, really important. It really lends I guess providers an insight into that patient experience and the patient's story. And now we're looking at actually incorporating them in various aspects of various different hospital programs. Whether that is through policy design, whether that is through sitting on various committees to inform the way that cares me because we understand that patients and families are the best person who understands their healthcare. And we need to be able to understand that and take that, that, I guess important insight and use it to our best I guess knowledge

Genia: So how are families to understand the trade off right now? You know, right now many, many families are being told that they can't accompany their loved one into the hospital. They can't even have visitors. So how are hospitals considering the trade off between the increased patient safety that is facilitated by family presence and the restrictions on visitors and family presence due to the pandemic?

Amie: I think what we have to understand is like you said, there is a trade off in terms of risk and benefit and really most organizations are moving towards, well one, they do have some places have that novisitor's policy. But we are looking at compassionate grounds, so allowing patients and families to be visiting based on compassionate grounds. Or we're looking atbeginning of life and end of life as well. And there are different caveats for different populations. So for pediatrics, some organizations have caveats or that pediatric population as well. So, and really that trade off is balancing that risk of introducing COVID-19 into a potentially I guess risky type of situation specifically with our pediatric or female patients. We know that, like I was saying yesterday, that they go from being well, well, well to increasingly so like decompensating or being very ill. So the trade off really is we want to ensure that their safety of not only your loved one but other patients that might be in that kind of critical type of situation in the NICU or in [inaudible] as well.

Sara: Yeah. And I want to say from a practical perspective, find out who your child's primary nurses because usually there is a nurse that is the primaryassigned provider for your child and he or she will know your child best because there may be nurses that are coming here and there. But if you can really make the connection and find out who that person is, they would often be the best person as your point person to ask questions about how your child is doing. If you, let's say your child has to stay overnight and for whatever reason you can't feed her the whole time. Even just calling on the phone to get an update before you go to bed so that you have that peace of mind to know that

your child is fine and that you can mentally just, you know, take a break before you go back in the morning. So I think there are different strategies that are evolving every day as to how we can tackle this situation. And I know even before COVID-19 a lot of hospitals would have family meetings. So whether this meeting can be facilitated virtually, I think everyone is trying to figure this out day by day, how we can use technology in order to still stay connected in the same way.

Genia: And you talked about, Sara, you mentioned primary nursing and every shift there's a nurse that's assigned to a patient and that patient is that nurse's responsibility for that shift. But primary care nursing, even in inpatient hospital contacts also can mean sort of a core group of nurses so that there's less disruption over the course of let's say a 10 days swing of nurses. Can you guys talk about that a little bit? What that is and what it means.

Sara: Yeah. So I think there's the first the first one that you've mentioned, which is primary nursing, which means of course every time a certain nurse is on, he or she would be assigned your child. But then there's also team nursing as you mentioned, where a small group of nurses that care for the same patients. So for example, when one nurse is leaving and a number of nurses coming, we would give report to each other. And if it's someone that's already familiar with her child, then there's that, I guess communication and understanding of that child already. So it's less I guess chance of things falling through the cracks because you've already made that connection. You understand more of that child's behavior and medically or physically what they need. So it's really just bringing more consistency to their care. And I think it's more reassuring for everyone involved that there is that group that sort of knows your child best. Of course you know your child best, but right is the second best thing.

Genia: Right. And is that something that you can request if it's not something that the hospital does just by part of their routine? Like trying to assign, asking that the nurse, the same nurses be assigned to your loved one?

Sara: I think it's absolutely something that you can suggest. And even on the other side, there are nurses that request to have certain patients because they know that, you know, they've made a connection or they were with the patient during a really stressful time and they want to continue that care and support the family as best as they can. So I think it's a two way street. You can definitely request for having a primary nurse and a nurse can also request to be a primary nurse for a certain patient.

Amie: Yeah. And I do want to kind of jump in there and of course we're using the word request. It is, it is just an ask. And I also want to build up confidence in all of the nurses that are typically staff should have the knowledge, skill and judgment to take care of any particular patient as well. So maybe for whatever reason, cause nursing shifts can be different. So there could be a day, day, night night shift or they can have something called a traditional line, which is like twos and threes. So there might be a possibility that the nurse that has had your, your loved one for two or three days might not have them again during those particular day shifts. But one of the things I think is really important is, is that transfer of accountability, transfer of care, and building up your colleagues.

Amie: So really what should be happening at the bedside is, I don't want to say it's up-selling, but it's really kind of providing the patients and families bysaying to them that, you know, yeah, I might not be with your loved one, but this, I'd give it all this information over. And this particular nurse is just as excellent as I am in terms of being able to administerclinical care to your child. So I do want to say that yes it is a recommendation and, and for the most part, I believe that organizations will be flexible to make that occur because we do understand something called continuity of care and that's really trying to keep the same care provider with that same particular patient.

Amie: But there are situations where that might not occur, where maybe that particular nurse might be assigned to that patient. Maybe they, they're changing the skill mix and they need to assign them to someone different or more complex or whatever the case may be. But I do want to also say that yes, you can request, but it is a request at the end of the day. And typically, and this is just my whole gritty nurses, I'd say that most nurses have the knowledge, skill and judgment. It's just about building that trust and rapport and making sure that the families understand that as well.

Genia: Yeah. Yeah. I don't, I rarely worry when a loved one is in the hospital, but the nurse won't have the technical skills. I do really worry though about the impact of, you know, of not having family there. You know, the, just knowing somebody well makes a big difference. And we also know from the research that continuity of care provider and limiting the number of handovers improves outcomes. So it's not just about the technical skill of the provider. We know that communication breakdowns and lack of continuity, increased error rates, which is nobody's fault. It's just sort of, you know, you're, it's a part of working with humans that this is an issue.

Genia: So, so what, so if you're in that position as a parent or as a family member where the hospital is saying, "Listen, no we're not, we don't allow visitors or family presence is not allowed right now." What are some of the ways that families might argue compassionate grounds or advocate for compassionate grounds? You said compassionate grounds is one of the, that's a term that you know, that the hospitals are, are using to express that they understand that some patients are going to be more impacted by a lack of family presence than others. So how do, how do you go about using compassionate grounds as a rationale for presence?

Sara: Yeah. I think the first thing that we need to talk about is the term compassionate grounds. So it is kind of left open purposely because we know that there are many situations that could be in that category of compassionate grounds. So as a parent, I would suggest be really rational about why you are advocating to be with your child. Because if your child has developmental delay or they're medically complex, this is different than being separated from a loved one that is, you know, aware of everything that's happening. So being really rational and calm, but also from about why you're asking for what you're asking for and giving specific examples of why you are advocating to be with your child. So if you feel like the separation is going to cause exacerbation of symptoms or possibly a violent outbursts, I think it's important to give concrete examples to the staff so that they really understand what the implications could be. And I think that in just, just preparing as much as possible thinking about these situations, good to talk about it ahead of time.

Sara: Because we don't know with COVID-19 what's going to happen. Everything is changing day by day. But even having maybe a short written document of what your child needs and why they need to be with their parent at all times. And I think like a lot of people just sometimes can't find the right words or they maybe don't remember everything they want to say. And so if you have a written document, it kind of lays it out there like, Hey, this is serious. Like I need to be with my child. They have certain needs that are more than the average person. And if you were to say type out a document that's one page, it could stay with your child in their chart. And that way you're not repeating yourself over and over as which, as we said, every time you do that, there might be some breakdown in communication where information gets lost or it's reported inaccurately. So maybe just something to consider. This is something concrete that you could do now you know, preparing for the worst case scenario, but hoping for the best. It's just a different way of looking at it.

Amie: Yeah. And I think also just kind of thinking about the trade off of risk versus benefit. I mean again, as parents and care providers, we have a a different type of insight into our child's not just their diagnosis but to some of their new Watts type of behaviors. And I don't even want to say that it might pose as a safety risk to the staff cause yeah, that might be a part of it, but it's usually actually what we're concerned about it as a safety risk to our actual child. And of throwing up my own example, like I have a child with a disability as well. And one of the, I notice I understand some of his nuanced behaviors way better than any clinical care provider would they? Like I was saying previously, clinical providers can provide the injection or give that medication. But for example, that process in terms of understanding and trying to one, keep my child calm or to be able to explain it in a, in a way that he might understand those skills can, are not translatable to clinical skills.

Amie: Those are something only myself as his parent and advocate can actually be able to provide. This is where I think advocacy is a highly important as a parent. And I think it's very important to say, here are the reasons why my child might not be safe if they're left alone and if, if I am not there to help provide that, that carrier. And again, like we had mentioned yesterday unfortunately these times we might have to actually bring out those pieces where we say, okay, you know, yes we are going to be staying here strictly with them. We will not be going out. I will do whatever kind of conditions that at the hospital may require for me to make sure that I can come and take care of my child. But here's the safety benefits for me being here. And I think outlining those things. Most PR, I would say that most people would understand that compassionate type of situation and you wouldn't get to know to, to something like that to those requests.

Sara: Yeah. And just building onto that. So if you make that request once and you're met with resistance, I would just keep being persistent, right? Like this is your child and you want the best for your child. So if you have spoken to let's say a nurse and you're not getting anywhere, I would ask to speak to the charge nurse. I was asked to speak to the manager or the physician on call. Like I would just keep slowly trying to move up the chain because we all at the end of the day want what's best for the patient. And if you're not being heard or you feel like your current centers are not being validated, it's perfectly acceptable to keep speaking to different people, even patient relations. All

hospitals have a patient relations department. So I think it's just a matter of speaking to the right person that can allow you to get the care that you need for your child.

Genia: Okay. So I have a couple of couple of thoughts, so many thoughts. Okay. I have a question. Who ultimately has the power in the hospital to make the decision?

Amie: That's actually a tricky question. So in terms of, do you mean in terms of whether you can have that access to be with your child?

Genia: Yes.

Amie: Who would ultimately make that decision? I mean,

Sara: You know, I don't, it's tricky because I don't think it lies with any one person.

Amie: Yeah. I believe. Because you can continue to escalate your concern of the chain of command. There's not any one particular person who has the ability to say yes or no. I, and I think it's so much about a conversation more than it is about a black and white rule or guideline that the organization is kind of presenting. And again, that's why I think it's really important to have a very clear picture. Orwhat I've kind of mentioned is healthcare providers understand through storytelling. So it's so important, and it's not even about even telling a compelling story. It's about telling a story about how you can involve yourself within providing care with your child to make sure that your child's safe. And I feel through storytelling is a very powerful and impactful way for people to actually understand what you're trying to kind of get across.

Amie: But when I say there's any one person involved in the organization that has power to say yay or nay, I wouldn't say so. I think there's a variety in terms of the chain of command. Like I had mentioned that you can escalate your concerns as far as to the, to the CEO. And I mean you can continue going even outside of the hospital organization, go to the OHA, you can go to the ombudsman. Like your concerns can continue to be escalated. It really depends how far you need to go. And I don't, and I personally don't think it would ever reach that far. I thinkmost of these concerns based on compassionate grounds as they said it is vague, can be explained away through communicating what your needs are and what your child's needs are.

Genia: And just for clarity, the OHA is the Ontario Hospitals Association?

Amie: That's correct. Yeah.

Genia: And so if a parent is in the hospital, they're trying to figure out how to escalate their concerns who can tell them what that state of the chain of command is or the argument organizational chart. So patient, patient advocate or patient experience is likely one place that would, that would be required to communicate that information to people if they asked. Is that right?

Amie: Absolutely. That would be your first kind of, like for example, if you've tried the manager, you've tried your, your first charge nurse or whatever. That would be kind of my next step. So your patient relations or your patient experience office would be the next place that I would go to in terms of bringing those concerns. The best person to kind of help redirect [inaudible], who's the next person that needs to be involved.

Genia: Yeah, I've had good personal experience when I've needed to advocate in, in hospitals with asking to speak to a social worker and have the social worker, they're not, they're not going to help me contradict the hospital. They're an employee of the hospital. But I've had really good support from social workers in understanding the way the hospital works so that I can be a more effective advocate. Is that likely just I got lucky or is that, is that a legit kind of, you know place one might turn if they're struggling to understand the system,

Amie: I think it would be a legit source because also they can provide aspects of care that might not necessarily be fully actualized. I think people have to understand that the care of a child or even just any loved one, it's never by one particular person. There's usually a care team that's actually involved and social work brings in some of those outside resources that people might not actually understand. Because when you're in a hospital, you, you're connected much more succinctly than you are until you go into the community. But that social worker can bring in, "Hey, they need an occupational health kit. They need they need theology", or other different types of pieces that can actually help bring support to you to say, "Hey, this is why I actually need to be here to help support my child at this particular time." So I think that's actually a really good resource to pull on definitely to bring. And even if there are other members of the healthcare team, so the OTPT whomever else, I think those are definitely resources that I would pull on to help bring support to why you might need to be that additional person to help support your child.

Genia: And my experience also when, I mean, whether it's been social work or whether it's been me identifying some ally, they may not have a lot of power in the system, but identifying an ally that is in the system to help translate my sometimes somewhat and angry. You know, I've found that to be really helpful. Like, if you can find somebody in the system that can both like help to get you to help you to kind of get ahold of yourself a little bit. I say that with the most like most empathy cause I have been there but also somebody who, so they are translating the system to you but they can also help translate you to the system. I found that to be really helpful. And I just want to loop back around to one of the things that you alluded to, which is this are two things. Being irrational, not demand, like like what you're, you are talking about risk. You're talking about explaining risk, not explaining what you want because right now in the pandemic it's not about what you want. And also just the piece related to that, which is that you talked about a little bit aroundbeing prepared to be uncomfortable and follow the rules however you can in order to ensure that you can stay. Like this is not this is not the time where you're going to be accommodated [inaudible].

Sara: Yeah. I think it's more like trying to navigate the system. And I think a lot of parents who have children with medical complexities are already used to that. But everything with COVID-19 has sort of heightened everyone's stress level. People are on edge for various

different reasons. So it's about being rational because you want to sort of speak their language like instead of just, you know, I, I just has seen it and I don't fault anyone for it. Just coming to the nurses station and screaming what your request is, right. That might result in a code white being called, which is a violent patient because now this healthcare staff are physically fearing for themselves.

Sara: So rather than approaching it that way, trying as best you can to keep your emotions under control and just really voice what the concern is in a way that they'll understand like, "Hey, my child may become combative if I'm not there with them. That is going to affect your safety. So this is why I'm saying I need to be with my child at all times or whatever your request is." And I think just circling back to what you said is finding someone that you can connect with on a personal level who can also advocate and maybe filter your message in a way that resonates with the team. So whether that be a social worker or occupational therapists or physiotherapists or nurse, you know, just someone that really understands you, that doesn't judge you and really can interpret your concern and make you heard. So I think that's really important as well.

Amie: And I understand that like, like what you were saying Sara, that everyone's tensions are high, right? Like everybody is kind of on this extra high alert because we're, this time is quite unprecedented. Yes, we have had SARS and dealt with that in the past, but we never had this kind of entire like lockdown where people were social distancing, quarantining where services were be limited or shut down. Like this is, this is an unprecedented time. And I think we have to all be able to realize that and, and appreciate that. And one of the things I kind of had mentioned is we have to try to be understanding and much more compassionate during this time because yeah, like your attention and your, your feeling of anxiety is just going to be high, higher than it would generally be. So for example, like, you know, the emergency department is kind of the entrance way or the path, the entrance path.

Amie: We're healthcare providers. So I can only imagine, and again, I'm not trying to make excuses for anyone's behavior, but I can imagine that those groups are terribly stressful, the emergency department and the ICU because of this influx of patients that they're having. And I understand from the other aspect, being that patient family coming in with your sick child to make sure that they're getting the care needs that they have, they need to have addressed with you being able to provide that support. So one of the things I just want to kind of try to get out there is to try to remember to be understanding and compassionate. Not saying that any particular person's behavior is inexcusable.

Amie: So, for example, if a nurse yells at you or you know, you yell at a nurse, of course those behaviors aren't necessarily going to get your point across the way that she wants you, especially if you want to be that advocate for your loved one. But again, presenting the information and then also being firmed to say, "Hey, this is how I can support my child and decrease the risk to and increase actually the safety of my loved ones." And I think we had mentioned previously that this doesn't just apply to your pediatric patient. It can also apply to a patient who may have cognitive decline or cognitive impairment or dementia. These adults are also at higher risk as well. So I think it's just really about

advocating and explaining how you will help support patient safety within the organization. Being able to be that extra person to be their to support.

Genia: Getting sick with COVID-19 is scary for anyone, but if your family member with a disability gets sick, there are some really significant extra layers of worry. I mean, our family members often have communication challenges. They require additional support just to get through their good days. It just takes more to support somebody with a disability well through a hospitalization compared to somebody who is generally able bodied and able to advocate for themselves and communicate with the healthcare team. And then there are all the questions that this pandemic makes even more complicated. Will you even be allowed into the hospital with the kinds of visitor restrictions that are currently standard. If you are allowed in, how will you advocate to ensure that your loved one gets the care that they need, especially if health resources are limited? These are very real worries. It's not some imaginary boogeyman, but real threats that people are already facing in some communities.

Genia: It's incredibly helpful for us to be prepared and knowledgeable about how to reduce the risk of illness, how to advocate for family presence at the bedside if somebody does become ill and if you are at the bedside, how to effectively advocate for and safeguard vulnerable people while they're in the hospital. I did like to invite you to join me for a workshop on medical safeguarding. We'll focus on reducing the risk to illness to keep people out of the hospital in the first place. How to advocate and argue to ensure that someone can stay with the person if they do need to be hospitalized. And we'll focus on how you can maximize safety, quality of care and comfort for your loved one with a disability as a medical advocate while they're in the hospital to register and find out more, go to goodthingsinlife.org/staysafe. My heart and my thoughts are with you all. I'm thinking about you every day.

Genia: Yeah. I think it's really helpful the idea that hospitals, when we're talking about these patients, safety considerations around measuring risk and arguing a rationale for family presence that these patient's safety principles while they are more, most often applied to beginning and end of life pediatric care, that actually patient safety considerations and arguments apply regardless of your age or stage in life. So I think that that's really helpful to know. And Sara, you were talking about you mentioned, you know, explaining to people that, you know, my child might become combative. I think there's very often actually aalmost any patient will become combative if you push them, if you push them far enough. And you know, I think it's been, it's a very common experience and concern that hospitals are really quite happy to use medication and physical restraints to keep their staff safe and to keep their patients compliant. And Amie, you spoke last night about a least restraint policy, which is actually something that I didn't know was common in hospitals. And I wonder if you could explain how, what that is and how families can use that as part of their rationale.

Amie: Well, most organizations have something is called as a lease restraint policy. And really what that is looking at is using the least amount of, whether it's physical, chemical type of restraint, and to try to kind of employ something called like gentle persuasion types of procedures to really kind of minimize that risk. Because we do know that when we apply restraints that there is harm that can occur. So most organizations have a least

restraint policy. The other piece that I actually didn't mention yesterday was restraints actually have are typically an order. So it's a physician's order that you actually need to apply and restraints. But I'm taking restraints off. You don't need a an actual order. So most organizations really are trying to move away from restraint patients because we know that restraining can actually lead to more injury or more harm. So really we do have these I guess policies and procedures in place and really even finding out and asking more questions about, "Hey, I understand that this is a policy [inaudible]. How can we apply this tomy particular situation?"

Amie: And also one thing that I didn't mention yesterday is also child life specialists. Not all organizations have them, but it is so important that if they do to request the child life specialists. Like for example, my son was having dental surgery at McMaster. We had requested a child life specialist because we knew that he would have to have a, he's going to have a GA. We knew that he had to be sedated with [inaudible]. But they were able to have the child with health kind of sit with us, support us while we were in the emergency, sorry, the or waiting area. I was actually able to go with my child all the way into the operating room until they fully were able to put him asleep. So I think it's about knowing what resources are available. And again, this is helpful when you have that health navigator or have some of these kinds of little things in your back pocket, but trying to understand what the policies may be in place and then other resources, so child life and whatnot to help support you in whatever particular situation you may have.

Genia: Let's talk about catching more flies with honey than vinegar and how families can just sort of use that. Really. just apply that strategy of recognizing that you're dealing with humans who are going to be far more enthusiastic about helping you if they feel like you're in this together rather than feeling like they're an enemy.

Amie: Yeah. So I think the bulldozer effect doesn't work for a number of reasons for most situations. So if you're coming in like a raging bull or like I think one of the examples we talked about yesterday was like driving your car into the organization so people can understand how frustrated you are. Those strategies are aren't going to work. You do need to have a level head. And I think one of the things Sara mentioned is really write down and [inaudible] so you actually have plan in place in terms of what you're trying to explain. Again, you can, like we said, you can catch more flies with honey than you can with vinegar. And I'm not saying that you have to be sweet as pie, but you have to be able to one, no, have the language and that tact and diplomacy to really explain your concerns. And then voice them in a reasonable, rational way. I think if you come at people angrily or very aggressively, you're gonna put people's backs up. And I think that's just a normal reaction in general. So I just think that have the information, make sure that you're rational presented but also be firm. And I think, and I think people would understand that.

Genia: Sara, do you have anything to add to that?

Sara: Yeah, I just wanted to say, I think we spoke a bit yesterday about giving feedback when you've had a bad experience, but also when you've had a really good one, because I can speak as a nurse that it does get back for the nurse. So especially if you've had someone

that provided really good care to you, it's always a good idea to let the manager know. And you know, if, when that gets that nurse, it really does make her day or her week because we're all being pulled in so many different directions on a regular basis that having that positive feedback and just really enforces to the nurse that she is doing a good job and that she will continue to provide good care to your child. So providing that in time feedback I think is important because if you are, let's say going to be in the hospital for an extended period of time, I think it really boosts morale to hear that you are happy with your care.

Sara: And even you know, telling other team members that you are really pleased with the care that you got from a certain individual. It just really elevates, you know, yourself as a person. So I think it's good to give good feedback and of course if you didn't have a good experience, I think there's many different processes for that. So we do want to balance out what you were happy with. Also what you thought needed some improvement. And just going back to the role of having patients on different committees, it's something that I would say in the last five years has really come to the forefront forhospitals as well as community care is that we really want to involve patients in all aspects of things that we're doing. So whether it be developing a new policy or a new program, we really want input from those that have been affected by it. So if you are able to turn a positive or negative experience into a way to facilitate change, it's something that is really, reallybeing more, it's, it's morein demand now I guess. So that's something I would, I would just suggest to anyone that wants to get more involved in making change. There are many different opportunities for that.

Amie: Yeah. Sorry, go ahead.

Genia: Go ahead.

Amie: I think people like to hear what they're doing well so they can continue doing that. And I think it's important for people to understand what they're not as well as so we can make those types of all the improvements. So I think yesterday I had mentioned that when, when there is an issue or an incident or something that or harm that occurs, we know that it's never ever person in particular that it's usually a process. So one of the things I had mentioned is the Swiss cheese model. So really looking at howthis harm or error had occurred, we'd have to actually line up all of the, the holes would have to line up in that model for that harm to occur. So really it's important for us to know those negativeor not as great outcomes.

Amie: So we can make those process improvements to ensure that that doesn't happen to anybody else. So I know some people might say, you know, you can make a complaint and nothing happens to it. It goes into the ether or whatever. But I think this is where it's really important to have those, the patient voice and the family perspective to kind of come in and give that feedback and maybe sit on [inaudible] and say, "Hey, this is how we can inform your care." And I think organizations are really looking to patients and families to give that feedback because it's, it's highly important for us.

Genia: Yeah, I think that's really important. And also probably not what's at the, like the front of people's minds right now getting involved at in a sort of systems level or on a

committee. And I think that, but I think we should kind of hold that in the back of our minds. There's going to be tremendous potential to improve our system based on our experiences of trying to work through this really stressful situation together. And I also, I need to specify that I'm, I am not a stellar example of staying calm and supportive when one of my family members is at risk. When I'm afraid, when I see things being done poorly, when mistakes are made when care is given in anything other than like the utmost gentleness and consideration.

Genia: Like I am not a good role model. So I just want to put that out there for everybody. I'm not judging, but I think from a strategy perspective, it is incredibly important to acknowledge, especially right now that every healthcare provider walking into a hospital right now is walking in frightened for their own safety and the safety of their family. They areexperiencing the pandemic just as a human and a citizen just like you are as a parent. They have vulnerable people. I mean, one of the things that's sort of equalizing about this pandemic is that there are very few people who don't know somebody who they're afraid for if they catch this, right? Like it's and so you are dealing with people who are walking around the world just like you.

Genia: Feeling just like you are, but who are coming to work every day worrying about not having enough PPE to do their job safely. You know, and they're still showing up for their patients. And I think we owe it to our healthcare providers to come in with that attitude. I think healthcare providers deserve to be seen through that lens. But also from a patient safety perspective, if you care about protecting your loved one in the hospital not being the thing that makes this worse for a healthcare provider or the person who makes this worse for our healthcare provider and actually who makes them feel better about the work that they're doing, I think is an incredibly powerful strategy. It shouldn't be taken lightly. And there's lots of things that you can do.

Genia: And even somebody like myself who's quite terrible at this one of the, a recent episode that I did on the Good Things in Life podcastI had Dr. Rhoberta Shaler on and she was talking about giving weather reports and these are like emotional weather reports, which was just sort of like, this is the state of the sort of cyclone in my body right now. You know, like it's, and I think that that is an incredibly helpful way, particularly if you feel like you're on the edge of losing it is you can start with a weather report and tell your story. And starting with a weather report focuses that like, it doesn't make it the fault of the person you're talking to, which is very helpful if you're the person listening to that weather report in that story. And also it elicits empathy from the person who's listening to you, which I think is helpful and you can continue that, whether it's positive or negative.

Genia: So if you have a positive experience, even if it's small, keep talking about it. Regardless of who you're talking to and if you have a negative experience, you can keep talking about it or not. But doing it in a way that allows people to move forward as opposed to saying, well, you and everybody you work with are just terrible and it's wrong. It gives them nowhere to move up from in the care, right? If you are communicating your conclusion that it's all bad. So anyway, I really feel strongly that particularly given that we're working during a time when there are valid reasons for restricting the number of people with a patient, we need to be bending over backwards as families to make it easy

to let us be there. And to be helping healthcare providers to do a really good job at caring for our loved ones.

Sara: Yeah, I think you touched on some important points, which I really want to just go back to is acknowledging your feelings. So I think for parents it's really important to acknowledge how you're feeling and even seeing it out loud, right? It just validates to the person you're talking to. Yes, I'm coming off as maybe a bit anal or I seem really uptight. Here's why. Because I've had a previous situation where this and this happened. So I think it's just really, again, going back to the storytelling, telling the person that you're speaking to, why you are a certain way. And again, giving them somewhere to go, like, I was really happy when you did this, but I think you really need to take better care when you do this, right?

Sara: Like, because of what's happened with my child's in the past and I want to make this a good experience for all of us. So let's just try to come to a common ground or common understanding. And I'm just going back to something that Amie and I have talked about in a past podcast was who makes the worst patients? And we as nurses, we know that we're bad and it's because we know and I think it's because we know how things should be done properly and we hold other people to that really high standard. So it's just a matter of recognizing and understanding that. And maybe even just calling out the elephant in the room, like, I'm a healthcare professional and you know, sorry if I seem like I'm picking on you a bit, but I just want us to, you know, give the best care to my child.

Amie: And I think Genia, you're being a little bit hard on yourself because.

Genia: Oh, Amie, you've never been my child nurse.

Amie: Honestly. But no, like I think you're probably being too hard on yourself because everybody, this is just the human factor. Everybody understands that mommy bear feeling or that you know, I'm trying to remember what movie it is, The Hunger Games where you know, you salute to your other parents who have children with disabilities that cause you understand and you've been there, right? Yeah. But like don't like we are all humans, right. We understand that emotions, intentions can run high and the reason that you're reacting that way is because of an experience or, or something that has happened to you previously in the past. And I think that's, that's okay to explain that to your healthcare provider. Because I would feel open to say, Hey, you know, I remember when this nurse was trying to catheterize my son and she was doing it inproperly and I, and he is crying out in pain and I was just like, "If you touch him one more time, I'm going to break your arm."

Amie: You know, like we get it. And I think explaining these situations brings out that humanistic type of factor and really can help build that rapport between you and whoever your care provider is cause. Because that's kind of gives them an idea of who you are as a person as well. That's, you're not trying to attack them. You're really just trying to make sure that you're ensuring that safety, quality of care for your child. And I think it's so important to communicate that and to share, to share those stories and experiences with whoever might be taking care of your child so they have a better

understanding why you might be like that. You're not this awful person or this angry person. You just want to make sure that the best care is received by your child. So don't be so hard on yourself.

Genia: Yeah, I, yeah, I, I'm not, I don't think, I don't actually think I'm being hard on myself, but I also, I feel very concerned for families who have vulnerable people because I also know that in times of extreme strain, okay, let me back up. Even when they are not extenuating, very stressful circumstances, humans also are prone to asserting their power. And many, many, many parent advocates have had the experience of having somebody within a service system, including health shut them down in a way that really is about shutting down something they don't want to deal with and they have the power to do it. And right now hospitals are well within their rights to shut that shit down. And it's very stressful. So I feel very protective about to, on behalf of or I feel very sort of, it is my position that as a parent advocate, you need to be extra careful to not get yourself kicked out.

Amie: Well, I think it's also about understanding, this is where I talk about the tact and diplomacy part, like understanding and explaining why you're there. Like I think if you come at somebody with, and I understand that tensions are running high, but if you, if you come at somebody like a raging bull, they might be saying no, just because of your attitude.

Genia: Exactly.

Amie: They're not saying no because it's something that can't be done. They might be saying no just because of how you're approaching the situation. And this is where even like for example, sometimes me and my husband play like good cop, bad cop, I'm always bad cop and he might be the person that I'm tagged in. Like he's my tag team part where I'm like okay I need to tap out cause I'm using my own rational ability to express myself and to be, to be good cop. And I think that's sometimes is a strategy that works too to be like, Hey you know what? I am at my wit's end. I'm about to be the person that they're going to call a coder way on. Let me tap some, put someone else in that might be able to explain themselves. Cause the other thing is when we get so anxious and our tensions are running high, we're gonna really, you really actually start to lose what you're trying to explain. So it's just like, okay, so now that I'm just a bumbling idiot, let me get someone else to try to explain what I, what I'm trying to get across really important.

Genia: Right. Amie, right now you can't tag somebody else in.

Amie: Well, I mean this is where I'm, I kind of look at the situation as every situation is going to be based on that individual. Like there's no cookie cutter approach that can be brought to like they can't just say, okay, so here's the approach and this is how we're going to apply to everybody. They can't do that. This is always going to be based on individual circumstances. So what's your individual story as to why you coming into to facilitate care might provide more safety to this patient? I think one of the instances we talked about yesterday was about an ultrasound. I think you said your, one of your friends or someone had down in they wanted, they were upset because their spouse couldn't come into the organization to, to see the gender reveal. I, it was, yeah, there's a

difference between, you know, something that's a nicety and something that's a necessity.

Amie: So most organizations have policies related to coming in and having ultrasound. It is a technical procedure. They're actually doing the tests on you. They're doing. So there's no risk to say, Hey, you know, Timmy can't come in to see whether you have a boy or girl, not a big deal. There's no risk to say, okay, we can't have this person. So they're going to look at services that they can kind of minimize and decrease that traffic flow. And that's kind of like one example where that's a nice to have. It's a nice to have this person come in gender reveal, it's all great, but it's not a necessity. Whereas explaining the importance of being that advocate and being able to be there with your child who has these additional needs as more of a need, a necessity versus a nicety is to have me being there, explain or keep my child calm during this procedure. It's not, it's not a nice to have for me to be there. It's actually a necessity. It's a need.

Genia: Right, But if you're just about to lose your cool, there's not going to be another parent there you can tap in right now.

Amie: Absolutely. But the thing is if you know that that's about to happen, you've got to tap your self out. Just like you have to walk away, right?

Sara: I think you need to just even take five minutes. If you can take five minutes and just collect your thoughts and just go back to the intention, right? So we know that, I'm just speaking as a nurse myself, we don't go into the hospital because we want to cause problems, right? We're going in with the intent that we want to care for people. You're coming in as a parent with the intent of protecting your child and making sure they get the best care they need. So if there's nowhere to go, there's no space, even just taking five minutes yourself to calm down and really collect yourself and think about what am I trying to accomplish in this moment? And just try to go back to that conversation with that frame of mind versus letting it escalate to where you don't even know where it's going and things are just spiraling out of control. I think it's just trying to get control of your emotions if that's the best term to use. No, just, just like I was saying, just making sure that we have the outcome that we set out to get, right?

Amie: And at the end of the day, I think what you're trying to illustrate is you want safety for your child, so you're looking at patient safety and I believe that that's the same goal that nurses have, that physicians have, that family members have, that we're all working towards the same goal. And I think if you continue to circle it back to the fact that this is what I need to do to keep my child safe, this is what I need to do to keep my child safe. No one can ignore that. [inaudible] Something that's ignored.

Genia: I'm trying to imagine myself like just as we're talking about these situations, the amount of tension I feel in my chest and my gut is like, it's getting quite intense as we talk about this. And I try to imagine how I would tap out and I, there's dozens and dozens of times whereno, nobody calls me this except my family, but my, some members of my family sometimes call me Jeanie. And the number of times my husband has leaned in and said, "Jeanie", and it's like, that's like, he's like, "You're crossing the line." You're taking this from advocacy to like, you know, whipping or something like that. You know what I

mean? Like you're just like, you've crossed the line and I try to imagine, I'm trying to imagine what I might do.

Genia: And the only thing that I can think of honestly is like writing up my plan of like this. This is my very reasonable rationale for why it's imperative to patient safety for me to be present and then actually writing down a plan for myself that says, if you were about to lose it, this is what you're going to do. And the only thing that I can think of is to write down, say like, tell myself, I will say, excuse me, I just need a moment and then put my head between my legs and weep. Like I honestly can't think having been in that situation where I am truly, like I'm seeing red, I'm no longer being rational. Like you were saying, Amie, like I'm no longer, I don't even know what I'm talking about anymore. I'm so upset. And I actually, I think that's maybe putting your head between your legs and weeping is after you say, excuse me, I just need a minute, is maybe not a bad strategy.

Sara: [Inaudible] Extra tool in your toolbox that you didn't have before this conversation, right? So that's one thing that might get you through in this really tough situations. So I think for anyone listening, just coming up with one or two last resort options, right, to just sort of cope I think is really important in this situation.

Genia: Don't be a code white folks. Don't be a code white.

Amie: And you know what, it's okay to be so upset that at the pinnacle after all of this is happening for you to put your head between your legs and cry because I think everybody is kind of trying to figure this out. Day by day, minute by minute, hour by hour. I think that's actually okay. And I think sometimes it's important to have that, that cry. Like it's just like this is what you need to do to bring your, to circle yourself and reregulate your emotions. It's okay to be like, you know what? I've had enough. Take a minute and just let it out. And I think understanding and recognizing that you need to do that is hugely important. Cause I think I can only imagine the type of stress and PTSD that people will suffer after this entire pandemic. It's kind of resolved itself if it resolve itself or whatever. I think understanding that you need those additional supports are hugely important and not to feel weak or less of a person if you do take that minute to sit in and cry to say like this is not okay cause that's okay. I think that's [inaudible]

Genia: Yeah, it may feel vulnerable but better vulnerable than getting your ass kicked out cause you won't get back in right now. Like this the

Amie: Yeah, I think that would be like the worst case scenario because then you really actually can't advocate for your child, but you've been physically removed or they're putting a note on your file because you verbally assaulted someone or whatever the case may be. You've now crossed the boundary where you can't, you can no longer help your child. So that's not going to help you as a person. So definitely don't cross those boundaries. Find a strategy that will work for you to say, okay, I know I'm at this point, I need to tap myself out.

Genia: Yeah, yeah, for sure. I'm sure many of the people listening to this will be like, "Wow, she's totally a hothead." I've never, I've never been so upset. And I hope that's true. I

hope that, I hope that that is, I hope that's true. But if it's not true and you've ever been in that situation or you can anticipate yourself being in that situation, I am very, very frightened for families who can't who find themselves not in a position to keep the healthcare team as an ally or at least a respectful opponent if you're, if you're truly in a you know, in a conflict with the team about decisions that are being made.

Amie: And that's why I think that open communication is so important. Telling your story, sharing it with whoever that care provider is and that that can really help them advocate on their behalf as well to be like, Hey, I know this family. I know that this is what this child needs because I've seen it. I've seen it during the care that this is some, this person, this individual, these family members doing something that I can't possibly give them. This is why this person's integral to this patient's care. And I think that having that open dialogue and that communication really can help actually like create that ally and that rapport with healthcare team.

Genia: So Sara, Amie, is there anything that we haven't talked about that you think is really important for family advocates as they consider advocacy in the hospital right now?

Amie: I feel like we kind of caught everything and even some more today.

Genia: Yeah. That's great.

Sara: Yeah. One last thing I would say is the people listening to your podcast, I feel like you've created a community of some sort. So for the parents that don't feel connected to others in the same situation, maybe just reaching out online and finding some support to parents who have gone through this already and maybe finding strategies that have worked for them to just put in your toolbox. So if and when this does happen, you can think of something to sort of deescalate the situation and bring it really back to what's best for your child.

Amie: Absolutely. Exactly right.

Genia: Yeah, yeah. That's great advice. That's great advice. And people definitely can reach out to me and to the other parents in my community for sure. If people are interested in The Gritty Nurse Podcast and in connecting more with the two of you, how would they find you?

Sara: Well, they can find us on Apple podcasts, Spotify, YouTube. We're on Google podcasts. You can also follow us along on social media. We're on Facebook, Instagram, and Twitter. So we're in a lot of places.

Genia: Great. And I'll make sure those links are in the show notes. Amie, Sara, thank you so much for joining me again today to talk about family advocacy and family presence in the hospital during this pandemic. I am really, really grateful for your time and your contribution to my audience and my community. And also just thanks so much for continuing to work through this really difficult time.

Amie: Thank you, Genia. It's been an honor.

Genia: Hi friend. If like me, you're worried about what would happen to your loved one with a disability if they were hospitalized right now and you weren't able to be with them to advocate for them. Then join me for the workshop that I have coming up on medical advocacy and safeguarding. You can find it by going to goodthingsinlife.org/staysafe. We'll be covering topics like how to create a reasonable and rationale for getting around no visitor policies right now and advocating for family presence at the bedside and how to be a good and effective medical advocate while you're in the hospital with somebody. I hope to see you there, goodthingsinlife.org/staysafe.