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**Navigating Healthcare Journeys: Therapeutic Strategies
to Enhance Child and Family Centered Communication
and Discharge Planning
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Presenters: Christina Connors, OTR/L; Jennifer Kelley, CCLS
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- [Fawn] Today's course is Navigating Healthcare Journeys: Therapeutic Strategies to Enhance Child and Family-Centered Communication and Discharge Planning. Our presenters today are Christina Connors and Jennifer Kelley. Christina is an Occupational Therapist and proud mother of two children. With 18 years of clinical experience she has worked to enhance the function and independence of children and adults in acute inpatient rehabilitation, home health, acute care, outpatient, educational and most recently private practice settings. Christina initially developed Child Inspired, LLC in partnership with artists John Donato after her young son faced a life-threatening illness and hospitalization. Based on her professional background in medical and educational settings combined with her passion as a family advocate she was inspired to develop developmentally appropriate child-centered tools that would help children visualize their progress throughout medical journeys. Child inspired outreach work to help children and families facing medical challenges is now driven by the Get Well Map Foundation. This nonprofit organization creates and distributes child-centered resources and works to provide collaborative training to pediatric medical teams in order to integrate medical education tools in a pediatric healthcare experiences and interdisciplinary discharge planning processes.

Jennifer is a Certified Child Life Specialist with 10 years of clinical experience and a proud mother to a young daughter. Jen currently works at Nemours/Alfred I. duPont Hospital for Children in Wilmington, Delaware. For the last eight years she has worked in the Child Life, Creative Arts Therapy and School Programs Department. She works collaboratively with pediatric oncology patients, families and medical teams at Nemours Center for Cancer and Blood Disorders. She improves positive outcomes for patients with chronic and medically complex conditions that require inpatient and outpatient treatment. She has a passion for working with siblings and facilitating family-centered support groups including the development and implementation of a 16 week sibling bereavement group in collaboration with Social Work. She's a coordinator of Nemours ACLP accredited Child Life internship program and serves as Chairperson for Healthcare Initiatives at Get Well Map Foundation. She is an instrumental chat and

family advocate among Nemours' interdisciplinary team of pediatric cancer specialists working collaboratively to facilitate child and family-centered discharge planning processes for pediatric oncology patients and families. Welcome to both of you and Christina you may start us off.

- [Christina] Thank you so much Fawn. Jen and I are very excited to have this opportunity to present today. Just to quickly acknowledge our disclosures. They're here for you on the start of our PowerPoint and we're gonna go right into our learning outcomes. It is our goal to achieve the following learning outcomes throughout today's presentation, that you will be able to define the key components of a child and family-centered interdisciplinary discharge planning framework, describe the use of methods and strategies to partner with patients and families to facilitate therapeutic communication and navigation through various stages of medical care as well as identify potential challenges, solutions and opportunities to integrate child and family-centered tools and methods into your clinical workflows and medical education across diverse patient populations.

So as we get underway, I wanted to share a very personal case study to highlight a family-centered perspective. Jen will be sharing another case study towards the end of today's presentation. Andrew's story is really the foundation of our foundation. His experience in our family-centered perspective is what inspired this work and the resulting collaboration between Occupational Therapy and Child Life. So six years ago, our smiley active five-year-old son became sick with a typical childhood virus. He stayed home from preschool and had a fairly routine on eventful appointment with his pediatrician. Within 24 hours his symptoms worsened and we took him to our local community hospital for further evaluation. The closest pediatric hospital or pediatric urgent care center is about two hours away from our home. He was hospitalized with pneumonia, started on IV antibiotics and admitted overnight as a precautionary measure. By the next day his symptoms continued to worsen and feeling uncomfortable with the level of care he was receiving, I began to demand quicker

assessment by the attending pediatrician that was on call that day. Upon her evaluation, she determined that his condition was rapidly deteriorating and he required specialized pediatric intervention at Nemours/Alfred I. duPont Hospital for Children in Wilmington, Delaware. He was airlifted arriving before we could arrive by car to meet him. The scariest experience of my life as a mother was certainly underway. A spiral of increased anxiety and intensifying respiratory distress resulted in the requirement of intubation and multiple days of ventilator support to stabilize his medical condition. As several days in the PICU, an NG tube, an NJ tube, central line and countless meds further testing revealed that he had contracted H1N1 flu which was contributing to his multi organ complications. Let me just say that COVID-19 has been a very unwelcome trigger of many of the fears that our family experienced during that time.

Our experience included child and parent separation anxiety largely as a result of Andrew's medevac flight, displacement from our home about two hours away, separation from his sister and our daughter, the coordination of care for our daughter that was required while we managed Andrew's hospitalization, medication errors and his father becoming ill several days into Andrew's hospitalization which required his home isolation and further precautions with our daughter that was in town to help care for her. And if we flash forward for post hospitalization just for a moment, beginning around three weeks post hospitalization, Andrew began to experience traumatic stress reactions, emotional outbursts, episodes of rage and aggression, elopement attempts, self-injurious and self-deprecating language, nightmares and re-experiencing. This disrupted his home functioning and his reintegration back to daily routines and his school routine. So if we go back to his hospitalization, there were many moments of hopelessness, primal fear and trauma but there were also moments where his life-threatening condition also became life-altering. We deepened our faith found tiny moments of inspiration and hope, stop caring about the small stuff and clung to the big but very simplistic goal of going home. One morning during PICU daily rounds, Andrew's attending physician indicated that he would survive but it was still too early to know what his recovery might look like. Still intubated and sedated my mama bear,

occupational therapist's wheels started spinning or possibly even raging. How do I help my son understand this medically complex situation? When they began to wean his sedatives, he will just want to go home, he is five, he doesn't understand time well especially in an unfamiliar hospital environment. So I called a dear friend and asked her to "do a craft project" to which she giggled. Only an OT would ask for such a request. I asked her to make a map, a symbol of the hospital, the starting point and a photo of our home at the finish, adding a road that linked the two images, Velcro and a matchbox car. Andrew still to this day loves cars and trucks. It became a visual representation of his journey, a source of dialogue and rapport building with many members of his medical team.

To this day, I remember one particular exchange like it was yesterday. His respiratory therapist, Brian came into his room to administer a treatment, Andrew was still intubated and unaware but as Brian got up to leave, he approached the map, pulled off the car and advanced it forward. He said, "Buddy, you've already rounded that bend." I stared at it for hours. Yes, you've already rounded that bend. Our sense of hope began to improve and I felt empowered to be actively engaged in whatever discharge plan lay in front of us. So this was our starting point and what inspired the development of the tools and methods that blend art therapy and functional communication to ease anxiety and encourage children and families that are facing medical challenges. So as we move into some of the data that highlights the need for therapeutic strategies that enhance child and family-centered communication and discharge planning, we think it's important to just note the trend towards increasingly complex discharges. We know that patients are discharging with higher-acuity needs, that learning and processing information is challenging for the child and family particularly auditory processing during periods of anxiety and overwhelm. We know that they're receiving increasingly complex information and discharge instructions as medical care advancements are made and how many written materials and handouts are typically provided to our patients and families. We know that they often have challenging environmental considerations and that they're often necessary caregiver and family transitions. So

each year one in four children will receive medical care for an injury resulting in millions of emergency department visits and hospitalizations. Nearly one out of every six discharges, about six million from U.S. hospitals in 2012 was for children ages 17 years or younger. And on average pediatric patients have an average length of stay of about four days with an average cost of over \$6,000 per stay. And we also know that in recent years, there have been significant increases in the number of children admitted with chronic conditions. So freestanding hospitals, children's hospitals specifically are where services are designed for children and which operate independently of adult focused institutions. General hospitals, on the other hand, care may be provided in a general inpatient bed, a dedicated pediatric ward or a children's hospital that might be nested within a hospital but it often shares resources with adult focused services. So in 2012, about two million pediatric hospitalization occurred in a general hospital and of over 4,000 hospitals in the U.S. 3,866 are general hospitals and 70 are freestanding pediatric children's hospitals. So we know that many children and families are often displaced from their home environment and their support systems to access the specialized medical care that's required in a freestanding children's hospital or if they remain in a community based general hospital, they may or may not have access to the same child-centered services. So are there resources in place within those two different settings and how can we help to bridge the gaps? While every child's discharge looks quite different pediatrics standards that were published in 2014 in the Journal of the American Medical Association indicate that high quality family-centered guidelines and processes can indeed be applied broadly while still leaving room for individualized planning. And I'm gonna turn it over to Jen who is gonna take over with our trauma-sensitive considerations.

- [Jennifer] Thank you Christina. So I'm gonna just dive right in and start talking about some of the data surrounding trauma-sensitive considerations. As you can see, the data currently shows that the number of adverse childhood experiences are really quite high. Also known as ACEs, the CDC defines adverse childhood experiences as stressful or traumatic events, including abuse and neglect. Additionally, higher ACE

scores are correlated with increased risks of some diseases as well as social and emotional problems. There are a number of risk factors that can lead to a high ACE score. However, medical trauma is typically not even assessed as part of a person's ACE score really leading us to believe that these numbers might actually be even higher. Something that is encouraging though, there are some protective factors for ACEs that can kind of help prevent some of those symptoms including parental presence and support, particularly during that health care experience. So an additional area of research that has been an area of focus is on post-intensive care syndrome or PICS. Due to the advancements in critical care medicine there have been a lot of improvement in survival rates and after a critical illness or an injury. So obviously this is very positive. However, there are some negative consequences including significant functional disabilities that may include new or worsening impairment in physical, cognitive or mental health status. There's also a term known as PICS family which is when the psychological health of family members of the patient are affected in an adverse way as well.

So as you can see here, research has found that PICS affects 33% of all patients on ventilators and up to 50% of those with an ICU stay of at least one week. So really quite high numbers of patients are being affected. Another concept we wanted to discuss related to trauma informed care is pediatric medical traumatic stress also known as PMTS. So while traumatic stress reactions associated with pediatric medical events began being described early in their beginning phases. In the mid 1980s, the first large multi site study was completed in the mid 1990s and was specific to childhood cancer survivors through Anne Kazak's work. So I'm gonna refer to a little bit more, she's really sort of the pioneer for the trauma informed care work that we're gonna be talking about. So since then, since the mid '90s, research has continued to expand in this area. The work has highlighted the significant impacts on patients which may include a lot of symptoms including the loss of recently acquired developmental skills, so some regression, the onset of new fears, or reactivation of old fears, reckless behavior, separation anxiety, and psychosomatic complaints such as stomach aches

or headaches. It's also interesting to note that in some children, particularly younger children, they may experience hyperactivity distractibility and increase impulsivity which sometimes can be confused with ADD symptoms or ADHD symptoms. So Anne Kazak's work, she talks a lot about an integrative model of the PMTS which really takes a family-centered approach and identifies the need for assessment and intervention for the entire family which also includes the siblings. When using the traumatic stress model it's less important to identify experiences as objectively traumatic and more about the subjectivity and really how that patient and that family themselves perceive the experience. This can include their perceived level of threat to their life, the likelihood of the event evoking fear and the overall level of helplessness that often patients and family members do experience through hospitalization. So overall, the healthcare team really should be keeping in mind that subjectivity plays such a large role in the patient and family's experience as well as all members of the healthcare team really constantly continuing to assess the patient and families perceptions on their individual experience and then provide support based on that and really making sure that that support is both normalizing and non-stigmatizing.

So the pediatric medical traumatic stress needs to be considered while patients are receiving their medical treatment as well as after they've received that. So really, after discharge, things don't automatically just go away. As Christina mentioned, within her family, all of the things that she was experiencing with her son long after their hospital stay had ended. So ongoing concerns should be monitored by whether it's parents, primary caregivers, the primary care health providers. So the pediatrician, educators, really anyone who spends a significant amount of time with the child and sort of knows what their baseline is, we need them to be the ones that are continuing to kind of keep an eye on things and monitor behaviors. One of the most encouraging aspects that's referenced in current literature is that positive outcomes can actually result following traumatic events. It's sometimes referred to as post traumatic growth which can include positive changes in self and relationships with others which really indicates this development of resiliency. Resiliency can be impactful when the child experiences

future challenges, whether they're medically related or not. So that's something kind of exciting and again, researchers really continuing to grow in terms of studying resiliency and what an impact an event can have on the future of that child. So I'm gonna turn it back to Christina now.

- [Christina] Thanks Jen. So if you haven't noticed, you will by the end of today's presentation that we love visual analogies. So this is the Get Well framework. This is really the result of Occupational Therapy and Child Life collaboration in this work. So as we kind of showcase this framework, we really wanna be thinking about the function of an umbrella which we typically notice about an umbrella, what is observable? Does it function? Does it keep us dry? Do we notice a colorful patterns, fun or bold colors on an otherwise dreary day? So our therapeutic interventions which will be illustrated as the water resistant fabric panels and our pillars of integrity which are gonna be illustrated as the ribs of our umbrella, help to shield many of the stressors, the raindrops that children and families experience during life's difficult storms. We know that medical teams may not be able to eliminate all of these stressors but we do serve a role to help keep them dry. And those stressors that were listed up top are just some of the many stressors that children and families experience during childhood hospitalization and are referred to a few that impacted our family personally during our experience.

So the next piece is we're gonna spend the bulk of our presentation focusing on these therapeutic interventions. So what did we provide? Did it lead to a positive outcome? These are the aspects that are most observable to and felt by children and families and they promote the positive outcomes within our healthcare organizations. So the next piece is these pillars of integrity that I mentioned and these are the outcomes that healthcare organizations try to measure to determine if our interventions were effective, they give our therapeutic interventions their strength, their shape, and their integrity and when they're in place they further enhance the effectiveness of our therapeutic interventions. They may be largely unobservable to children and families when the

system is working cohesively but they're felt significantly by children and families when a rib is bent or broken as it will impact the functionality of the entire umbrella. So this is our framework if we look at it as a whole and again, we are gonna focus more on these therapeutic interventions, we're gonna start with exceptional clinical care. So this is a slide that we're not gonna spend a whole lot of time on because we know that this is an absolutely critical component of intervention and we could spend an entire webinar just focusing on this piece and how it's specific to different disciplines. But we know that our clinical care must include evidence-based diagnostic methods, evidence-based treatment protocols, excellent clinical judgment and decision making, that staff consistency is critically important in the delivery of care as well as the ability to provide individualized care to children and families. And I'm gonna turn it back over to Jen for the next few slides.

- [Jennifer] Thank you Christina. So I'm gonna talk a little bit now about communication. So good communication is extremely important particularly in healthcare setting. This communication should take a multi-sensory learning approach in order to ensure that the communication remains child and family-centered as well as developmentally appropriate. When thinking about potential barriers to good communication in healthcare setting staff really should be proactive in preventing issues. For example, resources should be utilized to ensure that support exists for when there are language barriers. I think it can be easy to fall into the habit of using a child to translate or speaking directly to the family member in the room who does speak English, you know thinking that they will translate for you. But these are not acceptable means of appropriate communication and really should not be utilized unless the family is requesting this. Additionally, in healthcare, many people understand that medical jargon should be avoided when talking to patients and families. However, it can be easy to forget that some phrases become second nature to clinicians but it still at the end of the day might not be understood by patients and families. So for example, the term NPO or nothing by mouth. So that's something that's often used and kind of thrown around, I hear it lots of times every single day but

families may not understand what that means and we might forget that they don't know the meaning of that. So it's important to keep in mind that every team member really has to play a part in this and help families understand, read their body language because sometimes the families just aren't comfortable sharing that they don't know something or they might assume that they should already know that information. So they might feel dumb or, you know, inadequate. So really just kind of keeping an eye on that. Another thing to keep in mind is that all team members are gonna have different communication styles which is okay and that's sort of how the world is. But this can get really challenging when patients who have more complex needs have a really large care team or when they're moving from one unit to another within the hospital. It's really helpful to keep this in mind and acknowledge this with families and kind of learn from your co-workers to find out what works best for the family or what were some things to perhaps avoid.

So promoting the developmentally appropriate communication. It's really important, like I said, to kind of really keep an eye on body language when speaking to patients and families to help assess if they're understanding or absorbing all of the information. Sometimes patients and families aren't, like I said, they're just not comfortable being able to express how they're feeling about the learning process or understanding even simple directions and that can that can really be something that we can watch for when we're communicating if those things aren't verbalized. So, when using something like a medical mapping tool which we're gonna explain a lot more about in just a little bit, it's really important to partner with the patients to help them be able to identify their goals and their wishes, make sure that they, themselves they have a say in what's happening to them. And it's really an important time to identify what those goals are that the patient might have and talk about what goals they have control of, what goals they don't, especially for older patients but even really being able for the younger patients to have them pick a couple things to focus on. So for example, there are some medical goals that the team has for caregivers but maybe not necessarily the patient. So these things need to be completed prior to discharge for example, a new diagnosis

education. So the patient doesn't necessarily have control over that but their parent or their caregiver really needs to make sure that they have all that information. So just kind of keeping track of not only the goals but who is responsible for those goals as well. It's important to monitor the progression of goals and adapt accordingly when goals change. So for example, if there's a medical setback, there needs to be a rest stop or a pause or essentially, the patient does not move forward in their progression but they understand that they're not moving backwards either. It's important to differentiate between the setbacks that potentially could be impacted by the patient if they are not kind of keeping up their end of the deal. And then those ones that are out of the patient's control, perhaps something medical that changes and they develop fevers or something along those lines. So another way to really promote good communication is during medical rounding. It can be helpful to use this time to monitor goals but also to ensure patients and families are understanding the information they're receiving and that their questions are being addressed as well. So some families find it helpful to have a designated person to provide specific support before rounding to identify what questions they'd like to ask and kind of what to expect from the experience.

Again, to have support during the actual rounding process, someone to be an extra person to hear and absorb information and then even after rounds to assess the caregivers level of understanding and kind of relate it back to what those identified goals are that were previously identified. So now we're gonna move into the next area which is therapeutic play. Therapeutic play in the healthcare setting is something that really can allow children to express their feelings or concerns. It's an excellent tool to help them become familiar with medical equipment, it can help increase their understanding of what's happening and who they're meeting, it can really help children learn and practice coping techniques for challenges they may face from everything from experiencing a painful procedure to coping with chronic pain, really just a wide variety of hospital experiences. It can also provide a sense of control and mastery for patients to feel like they have a say to reenact something or to kind of feel that they

can help better understand something. It's really a great way for the child to communicate any fears they might have or misconceptions they might have that providers can really work through with the child even at a very young age. There are three main types of therapeutic play and they all have very similar goals. So there's emotional expression which obviously helps patients express what emotions are feeling. There's instructional play with which really has a goal of developmentally appropriate education specific to a procedure or a new diagnosis and then there's medical play. So that's really just utilizing all of the medical supplies, whether they're real or pretend especially for the younger kids to help them understand the things that they're seeing and again, goes back to that mastery and control. So these different types of therapeutic play all kind of overlap and have similar effects on patients and other children's such as their siblings which can be really beneficial. So it's important to note that research indicates that therapeutic play has a positive impact on the reduction of psychological as well as physiological stress for children when they're experiencing medical challenges. It's really important for everyone to advocate for therapeutic play as a tool for fostering those positive behavioral responses as it can greatly impact their future medical encounters. So, perhaps they had a negative medical encounter and often that continues to kind of keep playing out in future encounters.

However, if we kind of stop the cycle and can provide some therapy opportunities for therapeutic play, we might be able to help that patient or that child, sort of process all that happened to them and in turn allows them to hopefully have better experiences in the future or at least be less frightened by the possibility of having to have future medical experiences. Additionally, we know that play does not have cultural barriers so it can really be utilized with children of all ages, all backgrounds. Again, it just makes it an extremely effective tool when working with patients and their families. So when promoting therapeutic play, with these interventions there tends to be a continuum in which medical play and preparation sort of converged organically, basically, really just meeting the child where they are in identifying what would be the most helpful to them

in that moment for that situation. It's really important to include the entire family particularly siblings to assess what they know and therefore be able to anticipate any gaps in education. It's important to provide education and guidance to caregivers and staff, even to certain staff who are present for longer periods of time with the patient regarding the importance of these interactions and the benefits of continuing this play during and even after a healthcare experience. A lot of times we talk with families about let's see what happens you know, it's gonna take multiple times for them to kind of get comfortable for some patients in particular. A specific type of medical play we often use is needle play. So we allow patients in a very safe and specific manner to utilize needles on a doll or a stuffed animal and that can be frightening for families, that can be frightening for the child, particularly, they've had really poor experiences with needles in the past. And this can be something that takes a while to gain their confidence and to gain their trust that this is something that they can do and they can act out.

So let's talk about how we're gonna do this safely and sort of just guiding families 'cause sometimes there needs to be that little push, not all kids are gonna just jump right in and want to participate in exploring all the different medical tools that they have seen utilized on that they themselves. So in terms of the discharge planning process, it really can be a great way to assess that everyone in the family is on the same page and the same page as the medical team as well. That way you can help identify any red flags that might be existing. Often I'll encourage the continued use of these play interventions after the discharge process and really educate families on what to look for in this play. I suggest families keep an eye out for anything concerning. So for example, I often will send a medical play kit home with a family and I will ask them, you know, bring it out, put it up right near their typical toys and kind of keep an eye on, do they gravitate towards it? Do they totally throw it in the other room and they don't even wanna see it? So are they refusing to touch any of that medical equipment and, you know, it doesn't have to be the day after hospitalization or even the week after but just in the coming weeks to kind of keep a little bit of an eye on it. So it could be a sign that

the child's really struggling to process their hospital experience and that's when we noticed that often families might benefit from additional support. So, another really important area to focus on is the family and sibling support. It's paramount to remember that all members of the family are impacted by hospitalization. If we think back to Christina's story in the beginning, she mentioned her husband was affected and her daughter was affected, every single person in that family is impacted. So when looking at caregivers, often the staff take the caregivers lead on how to interact with the patient because we know that parents know their children best, we hear that all the time. But it's important to remember that the stress and the demands of hospitalization could really make it difficult for them to be able to accurately and appropriately provide information or support to the staff members. And sometimes they have feelings of embarrassment if they recognize this. A lot of times there's this internal pressure I should know how to handle my child in this situation or I should have control of the situation.

So really giving them the grace to accept that that's okay and we understand that not everyone's able to do that in their situation. Siblings, as mentioned earlier is an area of passion of mine and there's just so much research and evidence that numerous challenges are associated with having a hospitalized brother or sister in many realms, whether it's for a very short hospitalization and a one time deal to, you know, chronic hospitalization or really extended hospitalizations of a patient. For example, some of the most common challenges are pretty intense. They include sadness, fear, loneliness, jealousy, resentment, embarrassment, guilt, feeling isolated from their peers or their family members, confusion surrounding their siblings illness. It's really common for roles to shift during hospitalization and then after discharge as well. Often older siblings might need to take on more of a parental role, rules and norms might change within the family and the hospitalized child obviously often is positioned in more of a central role of importance, really causing a lot of feelings, often feelings of distress or confusion for the other siblings. These changes really could have long lasting effects on the family dynamics and impact all families quite differently. So in order to help

support the entirety of the family, there are a variety of methods that have been proven to be successful. So something that we use all the time in the hospital setting and has a lot of evidence to prove the value of it is the teach back method. It can be used with patients as well as adult caregivers, is really an effective strategy that encourages engagement in the learning process. It's helpful to provide a small amount of information at a time to allow families to process the information and really have an opportunity to ask questions throughout. Active listening is so crucial and engaging with families and it can be helpful to ask questions such as what have you as a family, tried in the past to help prepare your child for something big.

So when talking specifically about that discharge planning process, you really helping them connect to something that they've previously experienced even if it wasn't in a medical setting. It's important to again, go back to those goals, you're gonna hear that word so often throughout this presentation but those goals are so important and really make sure that those goals are constantly being incorporated to really make sure that everyone is understanding, you know, yes the goal is to get healthy and to get home but let's break it down a little bit more and kind of look at what specifically we're working towards. It can be so helpful to be creative when engaging with patients and families to really help make those connections and help information stand out to them. Around looking at sibling support, it's important to have meaningful conversations with caregivers to really find out what the siblings understand. It's important to normalize those reactions, to have a good understanding of, you know, that they're not alone in this. I often say this is what I see and other siblings have told me this or I've seen other siblings do that to kind of help families feel that sense of normalcy. When offering to provide support it's also helpful to think about what appropriate timing looks like so that caregivers aren't overwhelmed. Maybe that first date isn't the best time to talk about siblings and that's okay. There might be a lot of other things going on but knowing that that needs to slowly start being kind of embedded in conversations. So it's also important to think about what caregivers have already shared with siblings, ask them how they normally share information with their children at home. Again, even if

it's totally unrelated to the healthcare experience. So, when you're providing education to patients include the siblings so that they feel part of the process. But at the same time, they're also hearing the same information. Something that I find that's really kind of a cool way if you're not able to incorporate the sibling in the process of providing education is the next time if you can get the siblings in the same room as the patient, to have the patient tell or teach the other, the well siblings that you can kind of gain a sense of what that patient actually understands but then it also gives them a sense of pride often to be able to share something that they have knowledge about. And, you know, overall, having patience knowing that there's just only so much information that even patients and caregivers can understand at once. So knowing that it might require multiple sessions to get all of the information across. It's also important when you assess that siblings needs are beyond your scope, utilize your team to provide additional resources to the family. So if you're in the hospital setting, likely there are other psychosocial care members on the team that can provide resources.

Bibliotherapy is something that I use all the time, there's just a book for just about everything that whether it's diagnosis specific or an experience in the hospital. So just really kind of seeing what else is out there and being able to give something tangible to the family. Sometimes there's, it's the need for a support group so that other families can help share their experiences and again, provide that normalcy. And obviously there are times when psychology or psychiatry needs to be involved. So going back to that communication, you know, having really good communication with the other healthcare team members and helping families even understand that there are resources beyond hospitalization, beyond discharge that might be available to them. I'm gonna turn it back over to Christina.

- [Christina] Thanks Jen. So to build on Jen's points on therapeutic play and family sibling support we're gonna talk about the fifth therapeutic intervention which is meaningful goal directed activities. So as OTs, you know, this is so critical to the care that we provide. But we have to recognize that during an acute hospitalization the focus is often on caregiving, providing care making tasks easier especially when a child

is in pain or there's a fear response. And oftentimes, parents and caregivers that becomes their primary focus in those situations. So there's also, it's very common there to be gaps in differences in expectations among families and staff members. And then of course, cultural differences with parenting roles and response to illness. So, incorporating therapeutic play into meaningful goal directed activities, how are we building those goal directed learning and performance opportunities into functional activities? Into activities of daily living, functional mobility, play and leisure tasks. And then establishing goals. Really, you know, we talk about goals, we create goals all the time and as OTs it comes very naturally to adapt in grade activities but families really oftentimes are focused on the long term goal in a hospitalization and they really, given the level of stress and anxiety, they really need their healthcare team and healthcare professionals to really be able to break down and scaffold those short term goals for them. So providing opportunities for choice and control in unfamiliar environment and situations. So giving two to three choices, maybe it's of clothing, food, options, games, music, try not to overwhelm with open-ended questions but just provide two or three choices that help reestablish that sense of control.

- [Jennifer] So as Christina was saying, we really wanna encourage and motivate children and families to work towards that skill development from a modified normal. So, you know, sort of why is gonna fit in with how things currently are based on whatever changes had occurred in the hospital setting. So teaching, it's really important to teach skills that are needed for that successful reintegration to the home, school or community environment. So talking about it and thinking it through and really helping families be able to understand what to expect so that they can kind of plan and prepare for that. So medical mapping is a therapeutic intervention that is obviously near and dear to Christina and I's heart. So families can really have difficulty when they're evaluating the treatment course. There's so many unknowns and often there's no specific information, we don't have a discharge date, we know that it's coming and all that can feel really good to know that that's on the horizon, that can also feel really frustrating to not have specifics particularly for young children. So, I think that, you

know, bringing in these medical maps when we're seeing and noticing that a family is having those feelings of frustration is a great time to provide that guidance and empowerment again, being able to have something tangible that the patient can help understand what lies ahead of them, what can we focus on and what can we control? So as you can kind of see from the graphics here, the child friendly themes are really specific to various interests. There's one that has rows with race cars, there's one that's under the sea and there's a princess one so different things that, you know, being able to choose what's appropriate for that patient, what is gonna most resonate with that patient.

So using pictures or illustrations to personalize the board is something that we encourage patients to do. So something that if they wanna put a picture of themselves or they wanna have a picture of the hospital as Christina said with her personal story, she asked her friend to draw something that depicted the hospital and then at the end, a lot of times kids will wanna put a picture of their house or draw a picture of their house, something that might be that end goal. And even if home isn't the goal, that's okay too. As you can see as something that is really important to us is the neutral zone, as I mentioned previously, it's helpful to not make patients feel as though they have to take step backwards. So really finding a spot to kind of take a pause and the fun creative features of them apps, those pauses are really fun rest stops. So there is the pit stop for the cars where they can get their tires adjusted or realigned, they can get more gas in their tank, things like that to kind of help kids you see that analogy and can relate it to something that they understand. There are milestone markers which I'll talk about in a second that highlight individualized aspect of medical experience to incorporate those interdisciplinary goals. So as I'm gonna not show you, obviously, not all trajectories look so specific. So for example, in my population with oncology patients, there's a few things that we need that are gonna be the standard goals for our patients but a lot of times those trajectories are are kind of all over the place. And so we use post it notes, we don't have specific milestone stickers and we'll put up those post it notes that have goals from each discipline and often will color code them. So

Occupational Therapy goals are all in pink post it notes. Child Life goals are in blue post it notes and things like that and then we kind of tagged them along the outer edge of the board. Something that we really wanna make sure that it stays family and patient focused. It's easy for clinicians a part of this process to put all their goals up there, and then it sort of looks messy, and again, we don't want it to be overwhelming for that patient or their family. So this is a little bit of a video to kind of show you how the boards are utilized. Here we go. Okay, so these are some more clear pictures of the boards. They are all on 12 by 18 inch foam, they're sort of like a firm foam, it's really easy to maintain. It can be incorporated in the hospital setting because they are all able to be wiped down so it meets our infection control standards. And really, here it's showing that you can personalize it, you put the patient's name up there. We often have on the backside of this is sort of like a signature board so oftentimes will advocate that caregivers get the medical team to sign the board.

As I talked about, there is an area for pictures to really personalize it to make it feel like it's their own, it's a good opportunity to build connections with patients. So we do use these re-positionable stickers that match the theme of the board and that way you're able to kind of move along the road, sort of helping the patient kind of track their whole experience. And then at the end, we suggest that patients take their board home as something that they can use to really recognize what all of the progress they have made. This is another example of our pit stop to show you sort of that neutral zone where it really avoids the occurrence of having to move backwards. So instead, it's sort of an opportunity to take that pause. This has really been helpful in helping patients. It's exciting to see them understand the progress they're making and what lies ahead of them and really address any questions they might have and keeping it so that there isn't too much medical terminology. So during that rounding process, it's sort of like then translated down to their level of like, okay, these are the goals that we've got for today, let's see what we can and then, you know, maybe at the end of the day, let's move that sticker kind of talk about where we are on the map today.

- [Christina] All right, perfect, I apologize about that. Technical difficulties for sure. So milestone markers are a new initiative that Jen and I have been collaborating on as a visual medical education tool to help children and families map out the individualized components and goals of their care. So currently, we have cardiac milestone stickers and we've been working on pediatric oncology milestones as well as a Retinoblastoma Family Advisory Group in Canada. We've actually been working on milestone markers for pediatric eye cancers. So really, these stickers are small and we kind of targeting in different areas. I'm gonna show you an example in the next couple slides. But we really recommend applying one sticker, maybe two to three maximum at a time to the child's Get Well Map that provide families with this visual prompt basically of what's gonna help prepare them for the next upcoming milestone that needs to be achieved in order to keep moving that progression forward towards discharge. So they're designed to be applied in the sequence that best aligns with the team's interdisciplinary plan of care. And they can also be depicted in the neutral zone as it might be a milestone that must be achieved in order to end a setback or pause a medical progress. They're adjustable and removable, as many of the kids request that the milestones are removed after achievement because many of them are related to medical education and although important in the moment of hospitalization, many kids are really excited that this becomes a keepsake that depicts their child, their experience and their bravery and perseverance.

- [Jennifer] All right, so I'm gonna just keep jumping right in. These are some examples that Christina and I have developed for the pediatric oncology medical markers. It is something that we again, that we really think in color coding apparently because we color code a lot of our things. But we really wanted to identify the difference between clinical goals, ADL, or physical care needs and then social emotional. There are just so many things again that can get lost and jumbled in the shuffle and not really be super clear to a younger child. So we thought this way again, as Christina was saying, we could maybe pull one or two from each category and kind of have that highlighted so that it's easy for everyone to kind of keep track of. There's also medical education and

home transition. So really pinpointing what we know, sort of in my world, in the oncology discharge planning process, the key important things and what we've, you know, we've taken the experience of previously discharged patients and kind of gotten that input to see what matter to you, what was confusing to you and kind of tailor down and pull out the the meat of it into these specific stickers. So I'm gonna jump back into the case study that Christina mentioned in the beginning that I was gonna discuss. So in my work on the bone marrow transplant unit, I met Emily who was an 11-year-old girl who had mild cerebral palsy as well as a medical condition that required her to have a bone marrow transplant. So I'm gonna talk a little bit about her background and kind of give you a little snippet into her life. While Emily herself was bilingual, her parents only spoke Spanish. Both mom and dad were intact and they were at the bedside with her. They did live about two hours away from their home during a two month long hospitalization which is pretty typical for our transplant patients. Culturally speaking, her parents were very protective and wanted to do everything for her even before hospitalization. They wanted to feed her, they wanted to dress her, they wanted to make sure they sort of had the control.

As you can imagine, this was exacerbated even more in the hospital setting because she was sick at times and she was not feeling well but this really caused Emily to become really frustrated. They were stuck in this room and she was at this age where she's starting to gain a little bit more independence and here her parents are 24 seven around her, trying to do the best that they can but ultimately causing frustration. So another piece of the puzzle here was that Emily experienced a lot of body changes. So she lost all of her hair, she had prolonged bloodshot eyes, really, really red eyes for several weeks and these things caused her a lot of distress. Before hospitalization, when we met, we had planned that she was going to FaceTime her cousins who wouldn't be able to visit, she was very close with them. So that was sort of the plan, how she was gonna stay connected to them. And then when she started to have these body changes, she was like, forget it, we're not doing this, I don't wanna see them. She wasn't comfortable, she felt really embarrassed. So she had a lot of these non-

medical stressors but then also the medical stressors, obviously, getting a bone marrow transplant is quite a busy. There's a lot happening, she got really, really sick for a while and then she had all of a sudden had all of these goals to kind of recuperate and recover. So this long hospitalization caused a lot of effect on how Emily coped. And as it seemed, we knew that as she continued to improve medically, she would need these clear specific goals to help motivate her to reach her finish line of getting to go home. So what's typical for us, because this plan is a little bit more cut and dry and we have some things in place that we know we start talking about discharge for a bone marrow transplant patient about two weeks before they're ready to go home. So we decided at that point, let's put a medical map into the mix and really help Emily process sort of what her responsibilities are and what she had to do in order to get to the discharge point.

So for her there were things that really high on her list was maintaining her nutrition and her physical therapy goals. Emily was phenomenal. When I introduced the map to her she became engaged in the process right from the start. She immediately drew a picture of her bedroom as her end goal. She felt like that was her ultimate, she wanted to sleep in her own bed. We took some pictures of her that her mom had brought in before she had some body changes and put that up on her board. She actually put some glitter for her name, she really wanted to kind of like own her board as her own. So something that was really exciting is and now we do this regularly when we have these maps is we started using the board at the daily rounds so that Emily could stay on track as a concrete way to track her progress. So the team would talk on rounds using holding the board, the attending would have the board right there, pop those sticky notes up on the board for what those goals were. And then we'd kind of go back into the room, Emily would look at her board, move her, that's when she liked to move her sticker from the previous day. When she got her new goals, we put those up on the board and it was really exciting to kind of process that with her in the moment, and again understand developmentally what she needed to still do. She did develop fevers. And so we talked a lot about how this was not her fault and we took that pause in the

pit stop area. And this really caused her a lot of distress at first because she knew that that was gonna pump out her discharge date but we helped kind of talk through that. And again, we did not move her sticker backwards. She just stayed in that pit stop until she was fever free for two days and then we picked up where we left off. It really was a balance for her to know that she could still participate in some of her goals even though she wasn't moving forward. So that was kind of something that we had to talk a lot about. If she was feeling well enough, she still needed to eat, she still needed to take her walks and get up and get dressed for the day. But it was really exciting along the way to see how she could understand the progress she made and look back at all of the whole path that she had already kind of accomplished. It was exciting when it was time for her to go home, she took her map with her and it really felt like she used it as a trophy to represent all of her progress. And she definitely was one that wanted to get the signatures of all of the staff on the team. So it was exciting and she even add some pictures on it of some of her nurses and care providers.

So we're just gonna quickly wrap up with some of our outcomes. We know that creating this process for promoting high quality individualized care in a family-centered healthcare environment promotes positive discharge planning and really can shorten the length of stay, prevent re-admissions to the hospital, there's improved consistency of that developmentally appropriate medical communication as well as medical education among the interdisciplinary team again, keeping everybody on the same page. It can be very helpful in preparing families for transitions to different units within the hospital, out to a McDonald House and even their home. So again, it doesn't have to be that standard and goal of home, it could be something smaller, maybe we wanna go for a walk that day or that week and what goals we have to accomplish before we can even go for that walk. It really can help empower families throughout the entire discharge planning process which we know starts upon admission. And so really using the visual support of the maps that creativity can spark, that interest and engagement in the process. So child and family-centered care is really about improving the satisfaction and ultimately the outcomes of the patient and family experience. So we

know that this continues to promote high quality individualized care and as an effective means of medical education that is collaborative and really allows for engaged partnerships with families. And we continue facilitating those positive outcomes and it's something, obviously, that's really important to all clinicians and this is just another tangible tool to do so. I'd be remiss to not talk about some potential barriers. This is not something that I could say, you know, we do without any pushback there, here and there. There are definitely times where there's a disengaged child or family that sometimes it's not right for them. They need a second, they need a pause to kind of try something different and how can we, you know, we all sort of have those families we've worked with and so then we need to think a little bit more strategically and how to provide the best care for them. We all get stuck working in clinical silos and that communication sometimes falls by the wayside because there's a variety of reasons why that is something that we all need to constantly put effort and energy into being collaborative. There's always inconsistent staffing especially different units due to staffing differently and that can be challenging.

So again, having something that everybody can kind of make sure that they're all hearing the same information, so the more that we can do that, the better. Often there's organization demands or insurance pressures to get patients in and out. So we might not have the time that we want to be able to provide all of education and the appropriate means to do so. They're often lack of experience with medically complex patients and families and that can feel, you know, really overwhelming for those providers as they start to gain some of that experience but I think it's our job to kind of teach and help one another to get that experience. Sometimes there's unestablished, unrealistic expectations, there's a lack of resources. So obviously money, time, support, those are things that often can be hard to come by especially in the healthcare climate that we're currently co-existing in. There's also difficulty sustaining a child and family-centered focus. As I mentioned with the boards, there are many meetings that I sat out with high level nursing leadership at the table who would say like, this looks too messy for me, I just want the goals listed out and then we're gonna

check them off every day and really helping them remember like, yes, that's important, we have to all make sure it's clear and we can all understand the goals but we have to also engage this five-year-old child or this 10-year-old child or this parent who's really overwhelmed themselves or they don't speak English. So how can we turn those goals into pictures and that language barrier that we talked about early on that can be really difficult, but again, it's going back to that play aspect and that reminder that that is that universal tool that we really can utilize to our benefit. So, as we kind of mentioned all throughout advocacy is really important. Embracing, encouraging those new ideas, using your team, being consistent with one another and then as new research is developing really share and promote that among colleagues because I think it's exciting to kind of continue propelling us forward and then be a champion for that child and family-centered care aspect too. Sometimes when we fall away from it, for whatever reason, it will be that person to kind of speak out and say, like, hey, hang on a second, I have this creative idea, let's try this. It's not always gonna take more time or energy. Sometimes it just takes an additional voice. So that's our presentation. We definitely welcome questions, any feedback. Our contact information is up here. Thank you so much for joining us today, we really appreciate it.

- [Fawn] Thank you Christina and Jennifer for a great talk today. This getwellmaps.org, it seems like a great program and they both provided their emails so if you have any questions and you think of something at a later date, please feel free to reach out to them. Thanks again everyone and I hope everyone has a great rest of the day. You join us again on continued.com and occupationaltherapy.com Thanks everyone.