

FROM CCLS TO PATIENT:

A New Perspective on Child Life Support for Children of Adult Patients

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If you had asked me two years ago about the need for child life presence beyond pediatric units, I'm sure I would have had a positive take. Still, my recent personal experience showed me why having a Certified Child Life Specialist (CCLS) available to families on adult hospital units is so important. Even though every hospital provides medical care to parents of children, not all

hospitals provide child life services. I wondered what support looked like when there was no CCLS present for those children, and after being a CCLS for almost 25 years, I, unfortunately, found my answer while spending 7 weeks in hospital away from my children—the needed medical intervention: a heart transplant.

I spent two weeks at a local community hospital near my home, but my family was unable to visit while I was local and without much medical equipment. The remaining 5 weeks were at a hospital 3 hours from home. It was such a surreal feeling to be in a “big city” hospital, the hospital where I completed my child life internship long ago. What was hugely different this time was that I was now the patient! I was moved to the ICU and equipped with a ventricular assist device (VAD) that aided my heart functioning but required me to remain in bed attached to a great deal of equipment until the transplant could be complete. While the VAD moved me up on the transplant waitlist, there was no guarantee that a donor heart would be found in time.

Having been a CCLS for many years, I was able to provide interventions by phone or Zoom for my children, then 13 and 17. I spoke honestly with my children about my diagnosis, how I was feeling,





and what the equipment in my room looked like. There were times I wasn't up for using my camera phone when the kids called, but when I planned my calls, I was able to talk about my Swan-Ganz Catheterization (SWAN) as it was within the view being captured by my phone. I asked my kids questions and always answered their questions to the best of my ability. What concerned me was the idea that my kids were trying to protect themselves and me by not asking all their questions. What I hoped for was a CCLS who could support my children with those questions without concern for protecting me.

The ICU had a supposedly strict policy about not allowing children to visit the unit, but this varied depending on who I asked. Most patients on the unit were much older, and therefore the need for children to visit was minimal. My children had never gone longer than a weekend without mom being present, and we were now approaching 7 weeks with so many unknowns. I was told by the transplant team that there were "other ways" around the hospital's policy, but they varied based on the unit, the diagnosis, and the ages of the children.

I don't recall when, but at some point in my career, I crossed paths with one of the child life specialists at this hospital, and I was able to reach out to her through social media to begin a conversation about supporting my children for a visit. I felt very fortunate to know the role of child

life and to be able to advocate for a visit with my children. Still, there was fear that the transplant might not go well and that I would never have the opportunity to see my children again. On the day of my children's scheduled visit, the CCLS gave a quick overview of her role and began to develop rapport with each child. She shared her hospital contact information with my children and told them they were welcome to reach out to her at any time with questions, especially if they weren't comfortable asking mom or dad those questions.

The next time my kids visited was after my transplant and on a day child life wasn't in hospital. This visit required my entire family to meet in a lobby with my nurse present. There was no privacy, and I could see how uncomfortable my children were as I tried to explain the equipment that "traveled" with me in front of a room full of people. This was a very different experience from the bedside visit coordinated by our child life specialist. However, by this time I knew I was coming home, which decreased some of our anxiety. I am so grateful we were able to have child life support for my children to visit me during the time when we didn't know for sure that I'd be coming home.

As a CCLS, I now see the essential need for child life on adult units to support children in the meaningful ways that we are uniquely trained to impact. While I knew to ask child life for support with the visit my family and I so desperately

needed, I wondered how many other adults were unfamiliar with the role of a CCLS and didn't know this was possible. I wondered how many other adults on the unit were told the multiple and varying policies on children visiting. I should also note that I continued to encounter challenges despite my knowledge and advocacy. I wish every hospital, regardless of pediatric patient presence, had access to their own CCLS to support the needs of all their patients, not just those that fall under "pediatric" age requirements.

I am certain most children visiting a parent in an ICU or the hospital would benefit from age-appropriate interventions and education. I've worked professionally with so many children who weren't provided information before visiting a hospital, and many parents who were so overwhelmed that they didn't think to ask about what support was available for their children. Having someone uniquely trained to provide those supports, and to establish policies where visits include those needed supports, is something every hospital should have.

Looking back, I'm so grateful for the experience I had. First, I am glad that I knew what child life could do and was able to ask them to support my children in the ways they needed. My teenage children were able to spend time with me because of the presence of child life, and they were able

to hear from someone other than me what was happening and how they could be involved in my care. Second, I was grateful for having access to a CCLS who could step in to support my children when or if I couldn't, at a time when my non-CCLS husband was supporting their needs but very likely would have had a much tougher time ensuring their successful coping in those challenging moments.

I hope that this message is shared with all those hospitals without child life support designated for adult floors. Every hospital should consider where they are missing the most crucial needs of children and families and explore adding child life to their list of services for all patients, not just on pediatric units. Regardless of the patient's age, there is the likelihood of children and families needing psychosocial support within the medical setting, and family-centered care isn't possible without ensuring families have the support they need. Within the scariest of medical moments, CCLSs can provide what other specialties can't – a developmental focus on children, memory-making that involves every family member in meaningful ways, and ensuring families stay connected in the most challenging moments. One of my greatest memories from this time was being able to hug my children, and that was something that, even with my child life background, I almost missed out on

