

CSH Support Corner – Parent & Caregiver Blog August 2022



An Important Lesson I Loved Learning...

Hi to all the Moms, Dads, Caregivers and friends caring for someone near and dear with special health needs. I'm Pat, Kenny's mom. I love being Kenny's mom! Kenny is a graduate of Children's Specialized Hospital and there is no doubt that every interaction, medical visit, therapy session, Friday Night Fever event, and volunteer opportunity, helped him become the happy, healthy, living life large, young man he is today. Kenny has cerebral palsy and is a spastic quadriplegic. I wanted to let you know that, to set the stage to share something I wished I had done more of. I'm hoping maybe you will think about it and give it a try with your child.

Over the years my husband and I have been excellent caregivers - Kenny's words. What we didn't do that I wished we had, was teach and promote Kenny directing his care as best that he could. For example, I just fed him. I didn't tell him how I needed to position him, to put a little pressure on his tongue when I gave him his food, and put the food near his back teeth. I didn't ask him what food he would like first. I ran his plate. He never complained. When I would get Kenny in his wheelchair I would just get him in put his lap belt, harness on,ommel in position, and buckle his foot straps. I never let Kenny say mom, do my lap belt, please put my harness on next, buckle my foot straps, and please put myommel up. My husband and I just did these things without empowering Kenny to give direction. It was our way of giving Kenny the best care we could, and it was faster. Now that he is a young man though and we've grown confident in letting him go out with others who will be feeding, toileting, getting his coat on and off, etc., Kenny needs to be able to direct his care and advocate for himself. We are working on self-advocacy skills right now and I'm happy to share, Kenny is a very good learner. Here are some tips from me to you, for you to consider:

- Build self-advocacy skills into your IEP from a young age
- As best you can be a true partner with your therapists and providers to help your child learn and practice self-advocacy skills in whatever way they are able. *Don't miss an opportunity. One interaction builds on the next.*
- Help your child learn about their disability. Teach them about their medications, what their meds look like, what their allergies are. The more they know about themselves the more they can advocate for what they need.

Good news – Kenny's catching up! Now he always eats his mashed potatoes first!

