

Making Special Memories Sharing Coffee Frapes

By: Pat O'Hanlon

My son Kenny O'Hanlon has been a very special gift to me. He is a graduate of Children's Specialized Hospital and really doing well as an adult. I wanted to share something that happened this year and in particular this past Saturday. A few months back Kenny discovered Iced Coffee "Frape". Now our new every Saturday ritual is that we enjoy a cup of coffee frape together and talk. Usually, the conversation centers around a retro video game Kenny would like to find for his video game collection, or suggestions about what we might cook together for dinner. Recently Kenny has become quite a philosopher and loves to dive into deeper conversations with me. I love it!! The world according to Kenny can be very profound, sometimes hilarious, always interesting, never dull. I'm so grateful that we are so close. I cherish our mother son relationship!

During one of our recent conversations Kenny stated that he wished he didn't have cerebral palsy. The reason he shared is that he feels so tired of having to ask someone else to do everything for him. Feed him, get him out of bed, change a video game...These were just a few of the things he shared. He didn't sound depressed. Just sharing his thoughts. I listened and let him talk about all this. Inside I was thinking that I probably would never be as kind and thoughtful as Kenny is to all his caregivers. I know I would definitely get frustrated if I had to wait for help to do everything. Finally, Kenny asked me what I thought it would be like if he didn't have CP.

As usual, I was caught completely off guard. Kenny does have some cognitive impairment in addition to his physical disability but honestly, he is the kindest and wisest person I know. I had to take a couple minutes to think before I answered him. To stall for a little more time, I took a sip of my Frape and shared "hmm" this is so good. We both laughed.

Then I told Kenny I wish your life could be easier. I'm really sorry if I sigh and complain sometimes when I help you out, I don't mean to do that. I told him I can't even imagine how I would feel or act if I had to always rely on others for help. Kenny said "Mom it would make you crazy"! I shared with him that I was so proud of how he handled this aspect of his life. Then I added how much I love and respect him for the man he is. I told him I wouldn't want anyone else for a son. I reminded him of all the amazing things he has accomplished in his life and the wonderful people he has met and interacted with. The doctors, therapists, and teachers who have supported him and how all of them have become very special to our family. I told him no one makes me laugh more than he does. I talked about the impact he has had on his dad and me making us better than we ever dreamed we could be. I reminded him of the community he belongs to at his Adult Program and all his friends, instructors, aides that he would never have met if he didn't have CP. With my whole heart I told him all of this and so much more only happened because of who he is and CP is just a part of the man he is today.

This conversation made me realize a few things. I have read a lot about support for caregivers, caregiver burnout, mindfulness for caregivers and more. I have not read much about how our children feel about themselves or what it's like for them to interact with aides and caregivers and rely on them for their daily needs. I do know for sure that we are blessed and fortunate to be given the chance to be part of the lives of our children with disabilities. Watching how they manage their lives with their strengths and limitations and the impact they have on every person who meets them and interacts with them. I also realize how my son would never have become the special man he is if we didn't let all the special people

and professionals, we have met along the way, become part of our lives, listened to them, and value their expertise, support and friendship.

I'm going to continue to enjoy my every Saturday Frape with Kenny. Kenny gives me so much more than I will ever give him. Our children have to work a little harder, take a little longer, go a little slower, but they never get caught up in all the noise and distractions around them. Some of which we cause. They are just themselves. We can learn so much from them.

FYI add a little Carmel or Crushed Oreo Cookie to your Coffee Frape for an even more delightful Saturday jump start! You never know where the conversation will go!!



Resources:

The Princess and the Prosthetic:

<https://theprincessandtheprotheticblog.com/2025/06/07/how-to-help-your-disabled-child-build-self-esteem-and-confidence/>

How I Finally Learned to Appreciate My Body as A Person with Cerebral Palsy

<https://www.yourtango.com/2018310986/how-i-learned-self-love-person-cerebral-palsy>