

"Everything from hiring nursing services to assist at night with monitoring Morgan, to coordinating the in-home speech, occupational and physical therapy has been a battle."

home to sleeping out at a family or friend's house if one of them becomes sick, as was the case when Emma came down with the flu.

Reducing down from a two income household to one comes with its own challenges but the outpouring of support from the community has helped to ease some of those pressures that the family has faced. Families from the Center Moriches School District held a fundraiser at Atlantis Aquarium to raise money for the family. Morgan's school created Morgan Monday's where students wear tee shirts supporting Morgan and raising awareness as well as holding other smaller community fundraisers. "A girl at Morgan and Emma's school made hats for Morgan. It's been things like this that taught me about hope", said Emily. Morgan and Emma's dance school gave Emma free tuition to continue her dance classes, friends from the community posted on Facebook to find pool and yard maintenance companies to donate their services to the family for the summer and one of Emily's past colleagues connected her to a brain tumor survivor, Beth Ann Tillford, who raises awareness and money for brain cancer research. Beth Ann also visited the family while Morgan was in the hospital to help them decide on the Children's Hospital in Philadelphia and helped to put together a marathon on Long Island which raised money for Morgan.

When asked about what she would advise a family caregiver to do if he or she was thrown into a similar situation, Emily answered, "Accept help, even if you don't think you'll need it. Also, get a good therapist and reach out to the social workers and counselors that are available to you. It takes a weight off your shoulders and helps you to cope with the stress."

Morgan's progress is slow and steady. "Her speech is slow but it's coming back. Over the summer she couldn't move her tongue but now she can. She makes facial expressions and uses a lot of non-verbal communication to express her needs. She wants to play and stay engaged...and the other day she let out a belly laugh for the first time", said Emily. The family continues to reach new milestones and looks forward to Morgan having her Trach removed soon as well as her feeding tube.

When asked what has been the one thing that has helped you to stay strong throughout this whole ordeal, Emily answered, "We survive by staying in the moment. Being grateful for today and not thinking about tomorrow. In the beginning it was minute to minute."

If you want to help the Leary family with support or resources, please contact Emily Leary at m5225@optonline.net.

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