

Box 8: Burden on Child

[8a] Parent participant (10012): *"I remember she would wake up every morning, and she'd be just moaning...I don't know if it was pain or if it was...just foggy ammonia brain....She was just never normal.... It was just very – I don't know. It was very sad...It was day-to-day. It was hell. She would be stuck to a pump for an hour, and then we were still at that time trying to feed her orally. We'd sit her down at the table, and she'd sit for hours just trying to get a little bit of food in, and then by that time, it was time for another feeding. I mean, she had no life. She couldn't play. I mean, she was miserable...her thoughts were disorganized and cloudy. She wasn't a normal kid. It was heartbreaking."*

[8b] Parent participant (10018): *"That was one of the things in school. He learned how to count money, and that was a huge thing because he worked and worked at it. Then he had a high ammonia level...He remembered that he knew how to count money, but he couldn't count it anymore. We thought, oh, that quality of life's horrible. That was another one of the things that – especially he had to work so hard to learn it more than just a normal kid, and then to lose that functionality was devastating for him. That played into [the decision to transplant] too."*

[8c] Parent participant (10019): *"We didn't let her do a whole lot outside of our house, in terms of being normal, regular kids that can go play, and go swim, and go to school. We were too worried constantly about what she was going to get into, or was she going to burn too many calories, or was she going to wear herself out. We just kept her in a bubble. It was very stressful."*

[8d] Parent participant (10024): *"He's very active. He's very involved in sports...he plays football. He plays basketball. He plays lots of sports. [The doctor] adjusted his metabolic formula. She adjusted some things...He, obviously, is gaining weight. He's growing. His height, he's getting taller. He's doing so much better."*

[8e] Parent participant (10013): *"Of course, there's worry, but she doesn't live in a bubble and she never will. I want her to be out and about and to be part of normal life. It's just she's going to have to take more precautions than other people."*