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WHAT RESPIRE MEANS TO ME AND MY FAMILY

Hi! My name is Star I have multiple sclerosis and two children. My daughter is a teenager, do I need to say anymore! My son Parker will be 8 this March and has special needs. Parker is developmentally delayed. He is very strong for a 4'2" 58lb Boy. Parker shows no fear of the obvious and he will run and climb into any ones car. He just loves cars! Having MS I am not stable on my feet and can no longer run after him at anywhere near his speed! . I find walking difficult. My daughter and husband have picked up most of the work with Parker for me. Having respire gives us all a chance to rest and regroup as a family. It also gives Parker time to learn social skills with his peers and allows me to continue water therapy at Gaylord. One very important thing individuals don't realize is a special needs child takes a lot out of the healthiest person and that person is usually the sibling. Having respire allows me to spend quality time with my daughter and even my husband. My daughter needs and deserves her own life aside from helping with her brother.

It has been very hard for our family to get access to the respire services we need. Funding is very very limited. Time at the DMR centers is limited and not always available when our family really needs it. Parker requires someone be aware of him 24 hours a day. Left unwatched, he will run from the house and even down the street. My 15 year old daughter has taken on much of his care due to my limitations, but she needs time to be a teenager, and before we know it she will be going off to college.

My husband is put in the position of being torn between working extra hours, to make more money to afford the care we need, and coming home to care for me and Parker. Since MS is degenerative, my needs will only increase with time. For our family respire is very important so that each of us can enjoy time together, as well as time for our selves.

We support the work of the Ct Lifespan Respire Coalition in working to collaborate with all agencies in CT now providing respire , while looking to increase these services for all, as federal dollars become available. My family thanks you for your time and interest in seeing that Ct becomes a leader in true quality lifespan respire services for all caregivers in our state.

PLEASE! IMAGINE YOURSELF IN MY SHOES FOR ONE DAY.

THANK YOU!

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