

*The Haslinger Family Pediatric Palliative Care Center*

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To Whom It May Concern:

I am the nurse case manager for the Palliative Care Team at Akron Children's Hospital, a team which provides care on a daily basis for children with complex medical needs in our community. I am called upon to help families keep their children at home, where they can receive the best and safest care. One of the critical pieces that allow this to happen is the provision of private duty nursing care. Due to the medical needs and the potential for needed immediate intervention, each child is in need of eyes on 24 hours per day, 7 days per week. While they are stable within their own condition, they are at high risk for developing life altering complications at any moment. Without private duty nursing, parents are left without resources to eat, sleep, and care for the remainder of the family. This leads to fatigue, stress, and unsafe living conditions for the most vulnerable children, those with complex medical needs. Families must have the support of private duty nursing to care for their child in order to keep the family healthy and intact. Even the airlines recognize the need to care for yourself, before caring for others – their safety information includes a statement to the effect that in the event of an emergency, put your own oxygen mask on before assisting others.

These children and families often face prolonged and repeated hospitalizations while appropriate nursing care is found and those nurses are trained in the specialized equipment that is used for pediatrics. Each nurse is required to complete the orientation set by an agency and then receive training from a respiratory therapist from the hospital or from the home equipment company. Discharges can be delayed for weeks to months while staffing is obtained and training is completed. This causes a burden on the health care system as well as increased costs to the insurance companies, but it also adds to the struggles of a family that desperately wants their child at home with them. While their child is hospitalized, families have to juggle family life, caring for their other children, working, visiting the hospital to learn the care needs, and bonding with their child. Prolonged hospitalizations can cause delays in development, which further impact the health of the child and family throughout their lifetime. If staffing is lost once a child is discharged home, a repeat hospitalization may be required while pursuing nursing care to replace the nurse(s) that have left.

Thank you for your time, please feel free to contact me with any further questions.

Stephanie Allen, MSN, RN-BC, CHPPN, CCCTM, CPN