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Testimony to the Oregon Senate Interim Committee on Human Services regarding Hospital Visitor Guidelines for Patients with Developmental Disabilities

June 3, 2020

As a I watched the ambulance speed ahead to Salem Hospital with husband and son, I kept replaying the what the doctor at West Valley Hospital Emergency Room in Dallas, said moments earlier “Your son has pneumonia and is in critical condition, we need to get him to the ICU immediately, every second counts.”

What started as a quiet afternoon at home with my son was quickly transforming into the worst day of our lives. We thought it was just a chest cold with a cough, fatigue and fever, but when I noticed how rapid and shallow his breathing had become and how pale he had become, I knew something was terribly wrong. Although he can typically text message to communicate what he wants to eat, where he wants to go or exchange movie trivia, he’s never been able to tell us when he was sick or experiencing pain. Steven has a developmental disability of autism and does not use verbal communication beyond yes and no responses. So, whenever he requires medical care, his father and I are his voice. This was no exception.

Shortly after I arrived at Salem Hospital, my husband and I were asked to meet with the doctor who said that Steven had sepsis in addition to pneumonia and warned “We don’t know if your son will make it through the night.” We were in shock, but rushed back to the ICU room where our 24 year old son was fighting for his life and jumped into action to answer questions of the medical staff from things like how to best secure his IV, to problem solve how could access the oxygen he so desperately needed – the result was that for the next 48 hours my husband and I took turns holding a tube of oxygen in front of his nose and mouth because he would not tolerate any tubes or masks on his face. We were able to prevent the need for a ventilator and immediately attend to every need he had. We were a vital part of the incredible team that saved his life, and because we were both allowed to be at Steven’s bedside, we could share in the active care he required. After three days Steven was stabilized and was able to move to another unit

of the hospital, where he began to refuse care from the medical professionals and because we were there we could explain that this was his baseline, and actually should be celebrated as a welcome sign of recovery. We had the ability to negotiate with Steven to cooperate enough so the doctors and nurses could make an accurate assessment of his health. We were able to keep him calm and alleviate the need for physical restraint. After five days in the hospital, we returned home along with Steven – one of the happiest days of our lives!

This terrifying event was just three years ago, and although a lot has changed now because of the COVID pandemic, Steven's needs for family to be at his side, to keep him calm, relay critical information to the medical staff, and even hold the oxygen tube so he can continue to breathe – that has not changed. Fearful that we might be kept from accompanying Steven if he requires hospitalization during this COVID crisis, I consulted with our family doctor and in his words "Steven requires a support person so he can access his medical care and it would be a poor medical decision to prevent that needed support."

We ask that you require hospitals to permit a minimum of one essential support person / visitor at any given time with the ability to rotate with another designated support person at least every 12 hours to ensure that our son, and all Oregonians with disabilities have the support they need to access medical care at all times.

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