



FAMILY-CENTERED CARE IT'S WHAT WE DO

I met Tania in the PICU several months ago. She is a 16-year-old girl with muscle weakness, who had been intubated and on the ventilator for her diagnoses with pneumonia and CO2 retention. She had failed weaning off the ventilator several times. The PICU doctors told her parents the need for a tracheostomy and ventilator. These procedures would allow her to resume her daily activities and go home.

It was Tania's spirit and hopefulness however, that separated her from the other patients. Just upon meeting her, you could tell that she loved life. She looked forward to going back to school, seeing her friends, and being able to spend time with her 5-year-old sister Jessica. I admired this in Tania and it made the experience I had with her and her family more memorable.

I met later with Tania's entire family to provide them with the information regarding the tracheostomy and care she would need. This decision was very difficult for Tania and her family, for it would affect not only her exterior body image, but also the life style of the family. As they watched the trach video, and listened as I showed them tracheostomy tubes, speaking valve, and other gadgets associated for her care, the reality of it all began to sink in. The child life specialist also came to help Tania's sister, Jessica, understand the tracheostomy. She demonstrated the procedure using a doll with trach and suctioning via the tube. The family was encouraged to talk about their feelings and concerns regarding Tania's condition. It was important to involve all members of the family to learn tracheostomy care to lessen the stress on her parents. It would take a whole village to care for Tania.

A planned gathering with another family, who was already caring for a teenager with a trach and ventilator at home, was arranged. This meeting of these 2 families was a positive experience. Tania and her parents immediately agreed to the tracheostomy. Tania could not wait and said that she would like it placed by the next day. The child life therapist spent time daily with Tania and her sister, showing them dolls, catheters, and pictures to help them understand the care needed. Tania's parents also met with a social worker who explained to them the twenty-four hour care commitment once they returned home. They would need a variety of resources to help care for their daughter, including shift nursing, respite care, regional centers to access OT/PT/Speech, social work, insurance application for CCS, and financial aid available such as SSI, IHSS programs to lessen the financial burden of caring for a child with chronic illness (often one care giver must give up work in order to provide the best for their child).

While Tania was in the hospital for the next several weeks learning tracheostomy and ventilation care, I focused on her parents needs. We would discuss daily updates of Tania's progress and make sure all questions were answered in the language they are most comfortable with. I asked how they were sleeping to make sure they were going home to sleep and take proper care of themselves. If they were unable to go home at night or decided to stay, the hospital provided sleeping arrangements for up to several hours in order to secure a restful, and hopefully uninterrupted, sleep. It is important that parents are included in the care for they must absorb all the information and teachings provided to continue helping their child. Parents are also encouraged and reminded to eat. When things are quiet or while Tania was asleep, I encouraged them to walk in the garden or visit the meditation room. The chaplain also came on routine visits for spiritual support for Tania and her family. These activities were recommended on a daily basis for I had observed that Tania and her parents became more relaxed, cooperative, accepting and showed more initiative and willingness to learn.

After two weeks of learning, Tania and her family were showing confidence and independence. They were able to take Tania on her wheelchair down to the cafeteria, to McDonald's or to the garden. She and sister Jessica even received a visit from PAWS, a volunteer dog to uplift her spirits. Tania also attended school while in the hospital. It was such a pleasure to see how she tackled the homework given to her. She showed such maturity and responsibility. Tania's concern about her speech once she had the tracheostomy was aided by the speech therapist. For her parents it was music to their ears listening to her voice. These were signs of Tania's improvement. She was getting used to her new tracheostomy tube and even started teaching her sister how to suction her trach tube while Jessica sat on her lap. It was a beautiful picture to see! Her parents proudly watched both of them as they became confident and accepting. Tania and her family found new freedom with the aid of a ventilator and tracheostomy---she could now go to school and be with her friends. She was also looking forward going to college and being a teacher one day. Most of all she was looking forward to spending time with her grandparents when she goes to visit them in Mexico, who she wanted to visit in the summer.

The successful discharge to home was a coordinated effort by the doctors, social workers, nurses, speech, physical, occupational therapists, respiratory therapist and the care coordinators involved.

I watched Tania wheel herself out of the hospital armed with knowledge and confidence. Her family behind her with their love, strength and dedication. I felt that Tania's future looks bright. She and her family were able to handle all the challenges, living as normal life as possible. **A family centered care approach made this possible !!!**

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