Tube Feeding in School
by Brandis Goodman

As my daughter Raya’s third birthday approached, I had the sudden and terrifying realization that sending her to preschool for 2.5 hours a day, four days a week meant that someone else would be responsible for taking care of her, which would mean turning over the care of her feeding tube to someone else. Until that point in time, the only people who had ever touched her feeding pump and G-tube were myself, my husband, nurses at the hospital, and our respite provider. I knew that letting her go to preschool and, in turn, letting go of some of the control over her tube feeding was something that I would have to do eventually.

We did the best we could and made it through the first year, but it was a very bumpy ride. Going into her second year of preschool, the district built a new preschool facility with new staff, and we had an opportunity to start fresh and do things differently. Here are a few of the lessons that I learned.
Know Your School’s Policies

My anxiety over sending Raya to school peaked at our first IEP meeting when I found out the school district’s proposed emergency plan for accidental feeding tube removal during school hours. I was told over the phone by the district health supervisor, who was too busy to come to the meeting, that our school district had a “No Replacement” policy for feeding tubes, meaning that no district employee would be allowed to even attempt to replace the tube or put anything in the stoma to keep it open.

She told me that we had a couple of options. If Raya’s tube ever got pulled out, they would lay her on the floor and cover it with something and call me. If they couldn’t contact me, they would call 911 and send her to the hospital ER in an ambulance. The other option was, and I quote, “Or some parents just prefer that we cover it and they’ll take care of it when the kid gets home from school.” I picked my jaw up off of the floor and swallowed the swear words that were threatening to jump out and explained to them the reasons why NONE of those were good options for my three-year-old.

It was clear that they had little or no experience with feeding tubes. It was also made clear to me that trying to fight the district’s tube replacement policy would be futile, so we came up with a compromise that I was comfortable with. Our agreement was written into her IEP and also into the medical paperwork that the district requires, and I made sure to discuss it with anyone and everyone involved in her care at school.

Some districts do allow the school nurse or other trained individuals to replace dislodged feeding tubes; we just don’t happen to live in one of those districts. In talking with other parents, the amount of intervention school employees are allowed to take also varies. For example, one mom told me that her child’s school nurse is allowed to fully replace the tube, but another said that her child’s school nurse is allowed to either put in a Foley catheter or put in the G-tube but not inflate the button. Ask detailed questions and be sure that you are comfortable with your school’s emergency plan.

In addition to policies about tube replacement, every school district has slightly different rules about who is allowed to participate in certain aspects of tube feeding and care at school. In some schools, if there is a child with a feeding tube, a nurse is required to be on campus while that child is at school and is responsible for any and all feeding tube-related tasks. In other schools, teachers and health aides that are not nurses are allowed to participate in tube feeding. Some schools allow bolus feeds to be given in the cafeteria during lunchtime and others require them to be given in the nurse’s office. Find out what your district and school policies are and work with the school staff to come up with a feeding plan that everyone is comfortable with.

Meet with the Teacher Ahead of Time

This year, we met with Raya’s preschool teacher before the school year started. I requested a private meeting outside of the official meet-the-teacher day so that we could
have her undivided attention and discuss things in as much detail as we needed to. We brought her a typed summary of Raya’s medical history and gave her a copy of the Feeding Tube Awareness Foundation’s troubleshooting guide for the Moog Infinity pump.

Another thing to think about is that your child’s feeding tube may be the first one his or her teacher has ever seen. Meeting with the teacher ahead of time allows the teacher to ask questions and be given whatever information he or she needs in order to be comfortable around your child and feel confident caring for him or her in the classroom.

Meet with the School Nurse or Health Aid Ahead of Time

Having a meeting ahead of time with the school nurse or health aide is also a must. It is critical that the school nurse has extra feeding tube supplies on hand in case something breaks, clogs, or is otherwise rendered useless or accidentally left at home. It is also important that he or she knows what the supplies are for and is instructed on how to use them correctly.

Do not assume that the job of school nurse automatically comes with the knowledge of how to use tube feeding supplies. Your child is an individual, and although school staff may have cared for other children with feeding tubes, they have not cared for your child yet. Take the time to walk through any procedures that the nurse will be doing so that you are both comfortable with his or her ability to perform them properly.

Prepare an Emergency Kit and Extra Supplies

Our school health aide has three supply kits in her office for Raya, as well as her Epi-Pens. The first is her emergency G-tube kit. Although our school district has a “no-replacement” policy for G-tubes, our GI doctor and I both insisted that they allow us to keep a kit in the office with everything that would be needed in order to replace her tube if it was to break or come out. If I’m out of my house and don’t happen to have my kit with me for some reason, or if they can’t reach me and one of our back-up volunteers needs to come to the school and try to put her tube in, all of the supplies will be there.

This kit contains: an instruction card, a gently used MIC-KEY button (in case her AMT Mini One won’t go in or breaks), a Foley catheter (in case neither button will go in), an empty 6ml luer slip syringe (to remove water from her balloon), a 10ml syringe filled with KY Jelly, a 10ml luer slip syringe filled with 5ml of water for the balloon, split gauze to put around the tube, a stiffener for the AMT Mini One button, a roll of paper tape, nitrile gloves, and gauze pads for the school to cover her stoma with while they wait for someone to come. The kit is clearly marked with her name and “Emergency G-Tube Kit” and is kept in a plastic pencil box.
The second kit is her “Spare Parts Kit.” It contains an extra extension tube, a 10ml slip tip syringe for water flushes, a 35ml cath tip syringe for water boluses or flushes, and a box of Hypafix tape to tape her extension to her belly.

The third kit is her medicine kit. Raya has food allergies, so in addition to the Epi-Pens that are kept on site, we also keep a bottle of liquid Benadryl in the health office for her. The medicine kit also has liquid ibuprofen, a syringe to dispense medications, a syringe to flush the meds with, and a Y-port extension since we typically use right angle single port extensions for feeding. There is also a card with instructions for giving medications through the G-tube.

**Paperwork**

When possible, get copies of all of the forms your school will require you and your child’s doctors to fill out as far in advance as you can. Doctors can be slow in returning forms, and it is best if any and all forms can be signed and on file as soon as school starts. This is another area that will vary from school to school, but the forms that we had to fill out included an anaphylaxis emergency action plan, a G-tube feeding authorization form, a physician’s authorization for medical procedure at school form, an individualized care plan with emergency protocols for the G-tube, and the emergency information contact card that they require for every student in the district. Out of all of those forms, only two did not require physicians’ signatures.

**IEP/504 Plan/IHP**

Not every child with a feeding tube needs an IEP (Individualized Education Plan), but there are other options for ensuring that your child’s medical needs are accommodated in the least restrictive way possible. A 504 plan or IHP (Individual Health Plan) may be appropriate for children who are tube fed but do not need IEPs. This article from the Oley Foundation explains the differences between the IEPs, 504s, and IHPs and how to go about having one put in place for your child:  
http://www.oley.org/lifeline/IHP_IEP.html

Tube feeding can limit certain activities, such as games or activities in PE that require a child to lay on his or her belly, and in some cases activities that require running or jumping while the child is receiving feeds. Those are the kinds of issues that can be addressed in an IHP or 504 plan, or an IEP if one exists. It can also address where the child’s tube feeds are to take place and guidelines for minimal disruption of the child’s education due to tube feeding.

When writing an IEP, 504, or IHP, it is best to include anything that may affect the child while at school, whether it seems important at the time or not. For example, although the staff was aware of Raya’s food allergies, they did not seem to understand the importance of not allowing her to use foods that she was allergic to, such as dry cereal, for craft
projects in the classroom. It was a source of great frustration to me because I thought that once I informed the teacher, it was not going to happen again. We have since added specifics to her IEP regarding her food allergies and tube feeds. Having all of that information in the IEP means it can serve as a reference if school staff needs to be reminded, and that we legally have a leg to stand on if it is not followed. The more specific you can be in a legally binding document like an IEP or 504, the better off your child will be.

School can and should be a positive environment for all children, regardless of medical needs. The idea of turning over responsibility for your child’s tube feeds to someone else for several hours a day can be scary, but with the right amount of preparation and communication, it can be done safely and successfully.

For more information, visit Feeding Tube Awareness Foundation’s School page at http://www.feedingtubeawareness.com/TubeFeedingAtSchool.html.

Brandis is momma to Raya, the inspiration for her popular blog Feeding Raya, as well as 3 older children. As a photographer, she contributes to the all things multimedia at Feeding Tube Awareness Foundation. She also volunteers as a Tubie Surgeon for Tubie Friends.