Managing Tube Feeding and Infusing at Work and School Q&A
February 2023

Max Marti
Michelle Marti
Carol Cheney, BSN RN CPN

Q- Max - how do you and your mom/team decrease your risk of blood stream infections?

A- We do a sterile dressing change weekly and a cap change 2x week. If the dressing gets submerged in water we change it right after along with the cap. Our team prescribes Ethanol locks that we use 3x a week in place of heparin when disconnecting.

Q. Max - which type of G-tube do you prefer? What is the name of your nutrition formula?

A. Max said he prefers the AMT mini which is lower profile. It doesn’t stick out as far and doesn’t get caught on things. When he was a baby I (Michelle) preferred the Mic-key because it was easier to grasp when doing meds with a wiggly child. Max uses Kate Farms formula.

Q. No questions, just here to say thank you for sharing your story Max and Michelle! Max, thinking back to my own childhood when I was your age, I am so proud of you! Michelle, as a new mom, I can’t express the amount of respect I have for all the advocating you’ve done for Max over the years!

A. Thank you for your kind words!!!!

Q. I also want to thank you both for sharing your journey! This is so important for people just starting on theirs! Thank you! And thanks to Oley for making this possible!

A. We are glad it can help people starting their journey. We didn’t have much access to support groups (like Facebook, etc) when Max was born, so we know what it’s like to feel lost in all of this. We want to help others know that they are not alone and have resources! We also appreciate Oley!
Q. Max & Michelle - how did you handle gym class at school? what accommodations were helpful to have in place?

A. When Max was in elementary school, he wore a tight fitting undershirt under his clothes. We made a “tape-tab” on his line and safety pinned it to the inside of the undershirt. There are CVL covers you can purchase, but he never wanted to wear them because he thought they showed through his clothes too much and looked like “a bra”...also we used grip-locs and tape to secure the dressing and the line. The PE teachers were all aware of his condition and we had a nurse or an aide with an emergency kit (clamp, gauze, gloves, tape, alcohol wipes) in the gym with him. Now that he’s older and more responsible we use tape and grip-locs to secure the line to his body. When he plays sports like lacrosse he wears a chest guard (sports equipment). He carries his school backpack all day (for some reason kids don’t use their lockers these days), so now he carries the clamp supplies with him and there is no aide in the gym. I’m not sure if the question regarding accommodations is gym-specific or school related so I’ll answer a little of both. Max has a 504 stating that he can sit out of gym if he’s feeling tired or weak (he has NEVER chosen this). He has permission to go to the nurse whenever he wants. Some teachers use a system where Max just discretely places a laminated “pass” on their desk so they know where he is. He is very responsible, and the teachers trust that he is going to the nurse for a good reason. We have had many 504 accommodations throughout the years which have changed as he’s grown. The most useful one has been unlimited number of sick days and a homebound tutoring plan in case there are long absences. I’m happy to go into more detail if anyone wants.

Q. To Max and Michelle- What can your medical team help you with as you’re transitioning to adolescence and young adulthood?

A. Max said our medical team needs to do “everything” to transition us which means he doesn’t love me telling him what to do. I am super paranoid about his line care. His team started speaking directly with him about his condition at our appointments when he was about 9 years old. He would ask questions and they would explain his medications etc. He had been doing his own G-tube meds since about 5 years old (giving them, not drawing them up). He now changes his own g-tube button. Our next steps are getting him to draw up his meds and learn to hook-up & disconnect TPN. Our team is helpful in recognizing that we need to transition care and offers nurse training to Max regarding line care. I feel that they are also hesitant because of the risks involved. They are willing to work with our comfort level and I feel that he will listen to our team before he listens to me about line care. He will be going to high school next year and we feel it is important to have him proficient in line care so that he can have more freedom. I do wish our team offered (I’m sure they would if I ask) a zoom meeting with him every couple of weeks during the training time so he can demonstrate technique and they can go over things with him.