

We asked Texas Parent to Parent Families to share their EMS experiences (good & bad).

Here are just a few of their stories...

- ★ Our local Firefighters and EMTs... have shown great interest in being a part of my chronically ill son's health care team. In [our city] safety officers display professionalism, dedication, leadership and integrity.
- ★ At the beginning of every elementary school year, I visited the Firehouse/EMS site with homemade bread and updated the crews about [my son's] current health status. Because I am the daughter of a retired Firefighter-EMT, I know that multiple crews are assigned to each Fire-station and EMT bay. Therefore, I made visits to each crew on successive days. I wanted to ensure all team members received my personal respect and gratitude and instruction in advance of any needed care. In addition, the EMTs told me that they have an accessible data system that informs Firefighters and EMS personnel about my child's special health care needs. I requested a form and submitted this data to the ... EMS worker in charge of this data base. Moreover, the EMTs instructed me to post a neon colored sign on my front door which reads: Vial of Life. I was also told to put the Vial Of Life in my refrigerator door near the soy sauce and mustard and stuff. I have the clear plastic tube they gave me which holds a piece of paper describing [my son's] emergency health care needs due to peanut and latex allergies, current medications, diagnoses of diseases and conditions, and emergency contact physician which is [my son's] Team Lead Doctor. Fortunately so far, my son has not required the use of [our local] EMS services.



- ★ We are frequent flyers with EMS. We have had wonderful service. However, I was proactive in talking to not only the EMS director, but also to the station which services our house. Given the nature of my son's issues I think this was paramount in getting the best help we can. I think the key point is that even when it has been different guys responding..they have always been willing to listen to hints I give them for making things easier for themselves and my son. I also think having a ready, written list with medications...and also the last dosing times and dosages is huge for children on multiple meds. We have not been so lucky with our local emergency department, however, we have now worked out procedures with the local EMS to transfer him straight to the closest children's hospital. That took some effort, but is in everyone's best interest.



- ★ ..I think it's important for the paramedics to communicate with the parent as time and the emergency allows, to let them know what is going on, what they have done and what will happen. I understand if they are busy helping the injured person, but at some point (like in the ambulance) they need to talk to the parent/family member and explain the situation and

what they have done. I also do a lot of police/ emergency personnel training as part of my volunteer work for the Autism Society of — County, this is what we tell police officers: ‘talk to the parent/family member present, they know the person best and can give help on their particular behaviors, special needs, how to approach the person etc....It can avoid a lot of problems if you have this information.’ This is so important if you are dealing with medical emergencies, especially with a nonverbal child or adult, or one with cognitive or communication delays. My son is highly allergic to penicillin; he would not keep any tags or bracelets on him to alert emergency personnel because of his sensory issues (it’s better now) but unless they spoke to me or his dad, they would not have known...



- ★ This was in St. Louis, not Texas, so it's the idea here that counts: On our daughter's second-story bedroom window I placed a blue & white wheelchair sticker next to a tot-finder sticker. EMS came by after I provided information to them, and I showed them the double stickers which worked in tandem with the info in their computer.
- ★ Our experience with EMT services has not been great. My son has Down syndrome and has a trach. The EMS providers do not know enough about trachs. They would not take him without a trained person to go with them. You would think they would require this as part of training but I’ve found it to be real problem as a single parent with five kids. If I did not have the support system I have I would not have made it.
- ★ Our son was 14 months old at the time, and totally ventilator dependent. He had stopped breathing and all of our oxygen tanks appeared empty. We started bagging him and called 911. The fire department got there first, then the EMS, all the while we were on the phone with his doctors. We by then had suctioned his trach and removed a plug and he started breathing again. The doctors had us go ahead and change his trach tube. All of the medical personnel were still in our house and one wanted to assist the procedure. Another EMS or fire department personnel said no, just watch; and they did. We changed our son’s trach tube and everything was OK. (The EMS



personnel actually described it as “just like feeding a fish hook” – we’ve laughed about that several times over the years.) After everyone was leaving our house, one of the EMS/fire department personnel asked if they could come back and meet our son, at a different time and one not so stressful, because they would like to be more prepared and informed should we need to call again. We did arrange that meeting and gave them a picture of our son to keep at their station. Fortunately, we have not had to call them again yet – our son is now 17 years old.

- ★ When we lived in VA, the county allowed you to "register" with your local EMS company so that when you called your address was flagged. I am not sure how it all worked, but they were able to utilize the information you provided regarding your child's needs. Thankfully we haven't had to call EMS here, but I am sure it is only a matter of time. ♥