

Role: Patient's parent

You are the parent of 5-year-old child with rare genetic degenerative disorder, who has a tracheostomy and is ventilator-dependent with a gastrostomy tube, and admitted to the pediatric intensive care unit (PICU) overnight for respiratory failure and acute respiratory distress syndrome. Your son has been admitted to the PICU multiple times this year. Each time it seems the whole medical team wants to sit you down and explain to you that your son won't survive the admission, but he always seems to pull through. During previous hospitalizations, you have gotten very frustrated with the PICU's care, because they always mess up his home medication regimen (granted he takes like 8 different medications at all times of the day), they have to stick him about 10 times per day, and they barely move him. He just lies in bed developing bed sores, even though you make sure to bring his wheelchair each time.

During this exercise, you will act as a “difficult parent” (one who seems to micromanage or even obstructs treatment). The rest of the group will play the medical team. They will begin the exercise by telling you that your son is critically ill, and he will probably not survive the admission. They will ask you what you want to do if his heart stops – whether you want them to attempt CPR or not. You will tell them you are not ready to give up on your son and they should do everything possible to keep him alive. You will tell them you recently read of an experimental treatment online that you want them to try. You think this can possibly heal your child.

During the “care conference”, you should act very tense. After all, you've been through so many of these and each time it's just the medical team trying to convince you to pull the plug on your son. You don't have to say this out loud but basically you are thinking how they never see how happy he is at home. How much he smiles, for example. At the same time, you know that your son will likely turn around in a few days and you will be able to take him home. So, whatever you need to do to appease the medical team at this point is worth it. Still, you think how you don't trust them because they probably just wish he'd hurry up and die already.