

Normalizing the Abnormal

We were thrust into the world of chronic illness when I was five months pregnant, and it has been the centre of our life for the last 6 years. Mason has Hypoplastic Left Heart Syndrome. He has had his Norwood and Glenn, then we discovered he had pulmonary hypertension which has complicated everything. He was listed for transplant in March 2014 and was just transplanted at the end of August 2017.

I think that it took me awhile to realize how unusual our life is, as it is all that we have ever known. We do feel lucky though, because we still have Mason.

I wonder if you realize, however, that the things you see are not normal either? That you have also become used to an unusual world. There is a human need to normalize those things that we deal with everyday, otherwise, how would we cope?

People who are in the medical profession can sometimes fall into a trap. They feel that their ability to not react to a situation is the sign of experience. The goal for most medical professionals is to remain calm under fire. Some people think they are exuding this persona by not reacting at all. They seem unimpressed because they have seen worse before. However, to parents this is serious because it is their child.

Parents don't want medical professionals to act as if there is no problem. They are looking for validation of their concern and a plan to fix it.

Parents' most desperate times are often when they feel that something is wrong, but that nobody else seems concerned. Parents stare at their child and will notice something is wrong. This can be before a patient fits the usual signs and symptoms that textbooks describe. How can we use this information optimally?

I have some questions that I want you to ask yourself after you leave here today:

What are some ways that I can validate a parent's concern, even if I am not going to change my action? Can I accept my humanity? Can I accept that I may not always be the best version of myself and I may have missed something? How can I be receptive to input in these instances? What if I chose to believe my patients or families that there was something wrong or different?

What if a patient wanted a procedure done a different way or out of the norm, and there wasn't a risk or great expense – could I do it their way?

I want to express my heartfelt thanks that you chose the path of improving the lives of our children. It's not easy being in this world, but it's a better place because of people like you.

