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## What medicine can learn from pediatrics: A mother's perspective

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### Abstract

As a mother of a young adult child with Aspergers syndrome, as well as being a long-term patient myself (liver transplant in 2005), I have extensive experience in both camps. Recently my 20-year old son was admitted to a children's hospital for a twisted colon that had to be surgically reduced. As the parent of a child with special needs and related physical health-related issues connected to him being on the autism spectrum, I was naturally very concerned about him entering a hospital (perhaps PTSD based on my own experience at moments). Surprising to me, the experience was a very positive one. There were many "practices" I noticed among the nurses and physicians that reduced anxiety, embarrassment and overall stress amongst their young patients and family members who were there for them that ranged from signs on the door, the way they communicated with patient and parent(s), to the manner in which they explained the diagnosis, course of action or treatment and recovery time. All of these concepts or practices could easily be applied to treating adult patients as well. This article will shed light on ways pediatric medicine can positively impact the way we treat all people of all ages who are ill and hospitalized.

### Keywords

Communication, patient experience, previewing expectations, patient satisfaction

### Intent of Essay and Introduction

Often times in life, a challenge or difficulty can present itself and what can seem like an overwhelming cause to battle can teach us the greatest of life lessons and provide unforeseen gifts in the process.

My first medical challenge related to infertility and resulted in the becoming a parent none-the-less. When my son was born, we learned within his first two years that he was on the autism spectrum and with that came a host of research and experts who helped me in more ways than one. Less than five years after my son was diagnosed with Aspergers syndrome, I underwent an emergency liver transplant I believe was due to medical error during an earlier procedure. My outcome according to my surgeon was nothing short of miraculous despite months of hospitalization, rehabilitation and return visits due to innumerable complications. Today I'm alive and well.

It's my intent to share with readers the experience I most recently had with my son at a major children's hospital last year and the great things that are being done in pediatric medicine that can be borrowed when treating adults as well.

### Experiences in Health Care and What Can Be Applied in Other Medical Settings

One of my great life's physical and emotional challenges began in my twenties when I had a trying time both conceiving as well as carrying a child. I had undergone three miscarriages before my husband and I made the decision to adopt a baby girl from China. To say this was the best decision of our lives would be an understatement. Chloe AnYing Rose Goldstein (I know – that's funny, but true) was only five months old when we made the journey to China to meet our new daughter.

We were so fortunate to have a healthy and beautiful child. I was over the moon with happiness. It seemed a miracle to me that what began as great sadness (infertility) could end in such joy (parenthood through adoption). We had to wait six months before re-applying to adopt again, which was the plan. I remember specifically dressing Chloe up to take her to the adoption agency on the very first day of the sixth month to drop our application to go back to China and bring Chloe back her baby sister.

That night, I found myself exhausted, nauseous and asked my husband to pick up a pregnancy kit. He did and the following morning took the test immediately to discover that it showed positive for pregnancy within seconds. We decided to take a wait and see approach and happily continued on our path of enjoying our baby girl, hoping for the pregnancy to last and delaying (based on the pregnancy) the second adoption . . . for a bit.

My due date was July 4<sup>th</sup> 1997 and I like to joke that it was the one and only thing that Noah has ever done on time . . . and I was induced! I should have been ecstatic but instead, found myself in the midst of a post-partum funk that lasted weeks. It went largely undiagnosed and my concerns about myself, along with my newborn son increased with each passing day. I could tell, as sometimes only a mother can, that something was not quite right with Noah. He cried constantly unless I was holding him or he was in front of a television set – something Chloe had never seen until Noah was born. It seemed the only thing I could do to have a moment to take care of Chloe, myself, the house, make meals, etc. was to turn on the TV and get to the issue at hand.

I was told at every turn that “boys develop more slowly than girls” by his pediatrician when I’d mention that Chloe had hit certain milestones much sooner (despite the fact that she was in China the first few months of her life). “Do not worry” was the growing consensus amongst nearly everyone I spoke to including my husband.

When my son Noah’s motor and speech delays caused him (and the rest of us in the family) much frustration resulting in him having uncontrollable tantrums and behavioral issues we recognized these issues needed to be addressed. He would often hit, spit or go into rages and outbursts. Loud noises like police sirens or toilets flushing in public buildings caused him pain or discomfort as he covered his ears. He only wanted to wear soft clothing like sweats and would become agitated when wearing anything else. Crowds also bothered Noah, and we’d notice his “behaviors” increasing during these times.

Eventually, as my exposure to other babies continued – it was clear that there were physical and developmental delays. I found other mothers of children with learning disabilities who helped me tremendously and learned that Noah was presenting with signs of having autistic-like qualities. We got him enrolled in Early Intervention after we were told he wasn’t suited for pre-school and only wanted to swing on their indoor as well as outdoor swing. I found doctors who were recommended from other mothers who had children on the autism spectrum and I called immediately to get Noah evaluated. The wait lists were alarmingly long.

By the time Noah turned four we were able to have him assessed by a renowned neuro-psychologist, who diagnosed Noah’s symptoms as presenting like Asperger’s Syndrome – on the autism spectrum as suspected.

We sought out the help of a child behaviorist, associated with his office, named “Janet” who could assist us with Noah at home and at school. It was extremely stressful and ultimately required that we hire an attorney to help us

negotiate with our school system to offer Noah some of these services he/we desperately needed.

Janet came to our house very early one morning – 6:30am – just in time to witness me serving Noah his breakfast. As most mornings went, I placed Noah’s scrambled eggs on the table in front of him and he’d take his hand and throw the plate off the table leaving eggs strewn throughout the kitchen. I was at my wits end.

After Janet witnessed what happened she simply said, “Nancy, make him the eggs again and tell him that you’re going to give them to him, before you put it in front of him.” Ok. Not a problem. I obliged and made the eggs again and before I placed the dish in front of him, I said, “Noah, mommy made you eggs for breakfast, here you go.” He lifted his fork and began eating. *What?* Impossible I thought. How did this happen? What had I been missing all this time?

Janet explained that the breakfast scenario was a very short-term example of “previewing expectations.” In other words, by letting Noah know that breakfast was about to be served – as opposed to simply placing his breakfast in front of him – he was able to prepare himself for the meal he was about to receive. She shared that the concept of “previewing expectations” would work with everyone in my life. When you go to the grocery store with your three children (which happened far more than I would have liked it to) – let them know in the parking lot by saying “if everyone behaves and doesn’t throw things into the cart, (like they usually do), -- when we get to the checkout line, I will allow you each to get one candy.” It worked like a charm with all three of my children. I even tried it out with my spouse and friends and it seemed I was gaining agreement with ease.

Only recently, I’ve thought that if previewing expectations would work for a child on the autism spectrum, as well as typically developing people of all ages, how could this not work in all or any medical settings?

Fast forward to just a year ago when my 19-year-old (at the time) son Noah woke me up at 4:30am with excruciating pain and I immediately took him to our local emergency room. After tests and images were taken, within hours we were advised that Noah had a very long colon for someone his age and that it had twisted and needed to be taken care of immediately. I was advised to go to a major children's medical center in Boston, MA, and I'm so grateful they did.

The first procedure was to untwist the colon and see if they could avoid or delay the surgery. This process seemed to work, but within two weeks we were back for surgery to reduce the size of his colon which would mean surgery and a more-lengthy stay.

Noah was admitted to the ER at the hospital on a Sunday afternoon and was admitted later that day. The surgery took place a couple of days later and his dad and I took turns being on duty overnight and during the day.

The morning after Noah arrived at this children's hospital, I saw a metal plaque on the door as I re-entered Noah's room after getting a cup of coffee.

It read:

Please KNOCK on my door  
Please INTRODUCE yourself  
Please EXPLAIN why you are here  
Please TELL me if something might hurt

Wow! Instructions to the nurse or physician in the *voice of the patient*.

I thought this was ingenious for two reasons. 1. It's a great reminder to medical staff that there's a human being behind the door who may be experiencing this for the first time, or could be in for the long-term, but everyone deserves to be treated with respect and dignity. 2. The words were written from the viewpoint of the patient, previewing their expectation on what effective communication looks like from the patient's point-of-view.

This is a great reminder to all medical and non-medical personnel of what to say – or communicate – immediately upon entering a child's/patient's room. I believe there's much that can be learned and borrowed from pediatric medicine that can be applied to treating sick adults as well. Thoughtful and considerate communication is one of them.

Many of these ideas can be easily implemented with training and conversation. Buy in starts at the top of an organization and trickles down. Someone, a committee or group of individuals at this hospital at some point was able to put themselves in the shoes or beds of the pediatric patient and understand how they want to be communicated when a medical professional walked into their room.

It made me wonder if hospitals focused primarily on adults or elderly could implement as a reminder to anyone entering a patient's room on what to say to put that patient at ease through more effective communication? It's true children may be in the most vulnerable state when entering or staying in a hospital, but I know first-hand that adults can feel the same way.

I've had 20+ years of experience of being a mother to a child with physical and neurological challenges, but I've also been a long-term patient myself beginning in 2005. I

underwent an emergency liver transplant within one week of arriving at my local ER and being transferred the following day to a major Boston medical facility the following day. My new organ was a non-compatible blood type liver that came from a young woman in Appalachia, VA.

I was in a medically induced coma for two months starting just days prior to the transplant. When I awoke I had a trachea and was unable to speak. I remained in ICU for three months before being transferred to a rehabilitation facility for six weeks. Then, I was re-admitted to the transplant unit with a "failure to thrive diagnosis" typically given to end of life patients or preemies.

I remained in the hospital for more than six months and when I was finally discharged, I made 11 more returns staying anywhere from two to 11 nights each visit for various complications ranging from high potassium, two rejection episodes, aspergillum in my lungs, and on and on. I was in the midst of a marital separation and had been stripped of my health, home, children, work, dignity and was feeling like a shell of myself.

As a long-term patient there were many hours, days, weeks and months that I had time to think – a lot. I often felt that I was in a continuing state of not knowing. Not knowing about what the next procedure might be. Not knowing when I'd be able to breath on my own when I was coming off the ventilator (super scary). Not knowing when my family or friends might be visiting? Not knowing when my doctor would do his or her rounds and not knowing if they'd share any good news that day. The list was endless.

Miraculously, I have made a full recovery and am indebted to my medical team and the hospitals that I resided in during that year. I think that healthcare professionals and systems could benefit greatly if they understood the concept of "previewing expectations" by communicating effectively and with compassion to their patients and their families about what is to follow.

### **Reflections and Recommendations for Moving Forward and Applying These Communication Skills with Patients**

Imagine if – in the healthcare market -- every patient and their family members had expectations previewed for them so they had a good idea of what to expect – at the very beginning – during intake – or even pre-admission -- for example? What if the previewing of expectations continued during their (hopefully short) stay and prior to discharge?

When people know what to expect their anxiety levels decrease – their stress goes down and they have a greater

desire to be compliant. When stress diminishes, so do anxious conversations, demands and complaints on medical and non-medical staff. Money is saved and patients are more content. It's a win-win-win scenario. Stays may be shorter and readmissions might go down.

Knowing what to expect and what may be needed – a family member or friend to be with the discharged patient, medical appointments that need to be kept, open lines of communication with doctors or medical personnel so questions can be easily answered, are all helpful in shortening stays, increasing satisfaction and decreasing recurring admissions.

More communication – even repetitive communication – helps patients and family members better understand what your expectations are, and can prepare them mentally and physically for what's to come. Taking the time to communicate and preview expectations allows for more positive outcomes. It seems the hospital my son was at was doing its best to offer a gentle reminder in attaching that plaque to the door of who was behind it – an individual who would appreciate a more effective way of being communicated with and to.

I realize that healthcare providers want to provide consistent communication throughout the process and may be the ultimate goal of healthcare, but I also know first-hand that doesn't always happen. It was wonderful to see this happening in real time at a children's hospital where simple language was used, there was less rushing and more time spent in discussing my son's situation and generally had a different "vibe" than traditional hospitals – even some of the best ones.

The art and craft of previewing expectations, offering gentle reminders of how patients would like to be treated and spoken to, along with a willingness to spend time discussing a condition, treatment plan and aftercare is so essential. It goes such a long way in calming nerves, feeling respected and cared for creating an overall better patient experience. I say that from both a patient's perspective as well as a family member's.

What can you or your hospital implement that might be happening at a pediatric hospital? It is my hope that you are able to borrow some of their practices and apply them to yourself and your hospital. Happy patients talk about it after and that's the best kind of marketing – word of mouth and referrals.