

# What I Need Doctors to Understand When They See My Child With a Disability



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January 31, 2018

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Sometimes doctors make blanket statements about the future of our children with disabilities:

"He won't walk."

"He won't talk."

"He won't play soccer."

"He won't drive."

"He won't..."

These were all things said to me about my son, and when I talk to other mamas of kids with disabilities, they aren't surprised. They've heard it all before, too.

"He/she will have severe issues in the future."

"Good luck with that."

"You can be prepared that he will be dependent on you for a long time to come."

"There's really nothing else you can do."

The list goes on and on.

I haven't been to medical school, but I highly doubt there's *nothing* else we can do. The mama warriors out there have taught themselves a great deal of information in a very short amount of time and we might know about the latest research some doctors might not have heard of yet. We also know our children best.

Here are a few things I wish doctors considered when talking to us.

### **1. We have spent countless nights worried about our kids.**

We wonder what they may or may not do. Before seeing professionals, many of us have already typed a list of questions and grieved the fact our child may never walk or talk or drive, or whatever other thing the internet has told us.

### **2. You're the best? We know.**

That's why we're seeing you. Some of us may have traveled across the country to get to you (or at least emailed you 10 times, notified the hospital, called your secretary, found your cell phone number on our Facebook moms' support group page... you get the idea).

### **3. We've done our research.**

We've already wondered about and scoured the internet for every short and long term solution, medicine, drug, therapy, exercise, treatment, specialist and surgery that might help our child.

### **4. Our hands are tired.**

We've completed enough paperwork it feels we could replace the "Harry Potter" books.

### **5. We balance so much in life.**

Some of us need a planner so we can keep track of our schedule with all of our child's appointments and therapies. Some of us have to hire help or depend on family or friends for support so we can keep up with everything else going on.

## **6. We're medical experts.**

Well, sort of, because we've read the latest medical journals and learned everything we can about our child's condition. Some of us have applied to the drug, therapy, or stem cell program at a prestigious university that has a really long wait list, but we don't care, our child is going to get in.

## **7. We're fearless.**

Some of us may have seriously considered how to smuggle in the drug that isn't approved in the US because it's proven in other countries to be successful for our child's diagnosis.

## **8. We don't need pity.**

We've had enough people look at us with pity us, feel sorry for us and give up on us. We don't need one more.

## **9. We're tired.**

We've battled with the government, insurance, doctors, hospitals, therapists, employers, principals, counselors, etc. so our children get them the care they deserve while we try to maintain a career and a household and a marriage and our friendships. Please don't make this any harder, we're exhausted enough.

## **10. We pray.**

For those of us who believe in God, we pray all the time.

My son was 4.5 months old when, at a typical well visit, I was given a piece of paper from my pediatrician with a recommendation for a neurology visit the following week. On it, there was a diagnosis of “spastic hemiplegia/cerebral palsy (CP).” That’s actually how I found out my son had CP — from a piece of paper.

I don’t have to be an expert to conclude this isn’t how a parent, any parent, should receive a diagnosis for their child. If you are a medical provider, can we have an open, honest conversation next time? Instead of focusing on the negatives, or just ignoring us altogether, let’s figure out what we *can* do together.

Let’s start here:

### **1. Tell it to me straight.**

I need to understand what this means and what the best and worse-case scenarios are. I need you to talk to me about the diagnosis, not write it on a sheet of paper and hand it to me to take home.

### **2. Are there other therapies that may help?**

Besides early intervention, what other therapies are out there that may be beneficial for my child? Have you seen any success with other children and this therapy?

### **3. Are there books I can read?**

There is a library five minutes from my house. Are there books available on his diagnosis, or perhaps case studies that have shown an alternative therapy that may be of help to him? I’m open to anything!

#### **4. What about research studies?**

Are there any studies being conducted that my child may qualify for? I wasn't told from a doctor, but I researched and found a university about three hours away from us that was enrolling kids under 24 months in a CP study to help them with their weaker side. I signed up my son immediately, and we go this September (it's called Baby Champ for kids with hemiplegia). You can look it up.

#### **5. What about medical devices?**

Is there a piece of medical equipment available that may help to make my son more independent? My son met with a rehab specialist and she was able to put in an order for an AFO and SMO to help him walk. He is now taking steps supported!

#### **6. Are there specialists and experts in this field?**

Do you know anyone who specializes in this particular type of diagnosis or disability that I should talk to? Should we visit another specialist office in town, or perhaps somewhere out of the state or halfway across the country? Because we will go.

#### **7. Are there any surgeries available?**

If surgery is an option, what type of surgery? Are there surgeons you'd recommend? What's the typical recovery for this type of surgery? What is the success rate?

#### **8. I'd like to make him comfortable.**

Is there a medication or another treatment that may take away some of my son's physical pain?

### **9. Are there available resources in the community?**

Is there a support group or foundation where I can talk to other parents whose children also have this diagnosis? Can you help me out because this is scary, and a little bit of support from people who understand may just rescue me from feeling terribly alone.

### **10. Can you take just a little bit of time to help me on the next step of this journey?**

I'm strong, and determined, and I'm going to be my child's biggest advocate. Empower me.

The next time I am in an appointment with a doctor who says, "He won't" then I will look them and sigh. I'll be disappointed they've already placed him in the silo — the *no hope* silo. There are so many other things that can help my child. "He won't" is dismissive. Let's talk about what we *can* do.

I've met so many amazing children on this journey who had doctors and parents who didn't give up; they didn't accept "He won't" as an answer. They kept fighting with everything they had to get those kids the best care possible.

Let's keep up that fight. Together.

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*Original link to story:*

<https://themighty.com/2018/01/doctors-children-disabilities/>