



Complex Child E-Magazine

www.ComplexChild.com

It Will Be OK: A Primer For the Newly Diagnosed by Keely Schellenberg

It is a strange thing to feel relief when your child is diagnosed with a terrible disease, but relief is indeed the emotion we had. Parents of children diagnosed with progressive, life-threatening diseases often express the same sentiment, and often feel needless guilt over it. We've seen both sides of the coin, the world of undiagnosed, knowing something awful is wrong and not having a clue what it was, and the world of mitochondrial disease, still awful, but slightly less so in my opinion.

Having a name for the monster does indeed help.



You're in for a roller coaster, and as much as this ends one chapter of the journey, it also marks the beginning of a whole new one. Not more or less terrible/scary, but different. You will now spend the coming months learning how to be OK with the fact that things will get worse and you will not know exactly "what" is going to get worse until it does. The uncertainty does not get better, but it does get bearable.

You'll learn how to be OK with discussing this horrible disease, and you will reach a place where you can quite plainly explain that your child has this condition, it will get worse and there is really nothing that can be done (yet!) to stop it. People will be

horrified that you can talk about it without being a total mess...and I promise, with time, you will be able to talk about it without being a total mess!! It takes time, but you will get there.

You'll learn how to be OK with the fact that your child's life (and yours!) is now going to be vastly different than most, and it's just that. Not better, not worse, just very, very different. You will find joy in things most people don't notice, you will lose sleep over things most people don't even think about, and you will cry (both happy and sad tears) over things most people would never comprehend.

You don't know it yet, but your entire world and everything you thought was important before has been fundamentally changed. Nothing will ever be the same.

I promise though, with time, patience and support, you and your family will get to a place where it's OK. You may not be able to beat your child's illness, but you absolutely will grow from it, in ways you can't even imagine yet.

Be kind to yourself and be patient with your spouse, as he will likely process all this in a completely different, incompatible way than you, and it will upset you when he muddles through it differently. It's just that though, different, no more or less right. Allow him to get through it how he needs to and ask him to allow you to get through it your way. The same goes for all of your family.

Be prepared to lose friends. Be prepared to find amazing friends in old acquaintances you never expected. Be prepared to be let down by people you believed would be there no matter what, and be ready to be surprised by the ones you didn't.

Learn how to ask for help now, and do it specifically. Come up with a list of things that are difficult when things get bad (laundry, cooking, etc.) and ask friends and family to help out in those areas when things are rough. People WANT to help, but they will always come to you and say, "What can I do?" At a crisis point, you will not be able to tell them, so tell them ahead of time. Tell them when things are bad, you really need someone to come clean the kitchen and throw some laundry in, or deliver a meal or two. Help them help you.

These are all the things I wish someone had shared with me when we started this journey; we have had to learn them on the fly instead. We're getting there, but every year brings new challenges, new bombshells and new lessons, along with new joys and achievements.

It will be OK.

It will never be the same, but it will be OK.

It has to be OK.

Keely Schellenberg has a seven-year-old son Brandon with Mitochondrial Encephalomyopathy. She and her husband Dave and five-year-old son Tyler are "OK."