



How to Turn Pain into Beauty

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I am an American who has lived in Prague, Czech Republic, for 16 years. My wife, Anna, is Czech. I'm from California, born not far from Disneyland. Anna and I had never considered the possibility of cystic fibrosis; we had always figured that the odds of the two of us getting together in the first place would have precluded anything like CF happening. When our daughter, Joey, was born, we noticed signs that in retrospect were telltale for CF - frequent, greasy stools, and a skinny body with a pot belly. When we finally told our pediatrician about the greasy stools, she recommended a sweat test, which indeed came back positive for CF.

The time of the diagnosis was terrible for several reasons. The city of Prague was being hit by major flooding, and the constant, neverending rain was almost an expression of the desperation we were feeling. But somehow Anna and I set out to deal with Joey's CF diagnosis not with fear, but with hope and positivity. We figured that no matter what happened, at least we would face things knowing that we never held anything back, and never did things at less than 100 percent. Nothing can stop us.

This approach has meant that we've gone with Joey into some situations our CF doctors would probably rather not know about - visiting a pig farm, for example (she wore a mask, for what it's worth), or traveling to various cities around Europe and visiting California. We don't seek risky situations, but instead we try to make decisions based on rational evaluations of risk.

As much as possible, we try to add fun to the daily routines connected with CF. We've found that for airway clearance, for example, tickling tends to bring up more phlegm than just about anything else. So there's lots of tickling and laughing. When Joey was smaller, we only let her watch cartoons when she was doing inhalations - at one point she asked if she could do inhalations so that she could watch a favorite video.

Joey's very interested in superheroes, so we've talked a lot about how a lot of superheroes got that way because of their mutations. We always tell her she's special, and that if she works hard, she can have super breathing powers. This isn't to say that we've convinced her she's a superhero, but she still likes to wear capes anyway.

As much as possible, we tell the truth with her and try to teach her to tell the truth with us. This can often be hard, as we tend to come up with answers to her questions that are too long for an 8-year-old's attention span. But at least we aren't sugar-coating the situation; we think that this will lead to her development of better coping mechanisms. It also leads to fewer conflict situations in later years, as we aren't hiding anything from her.

Life with CF is a marathon, not a sprint. Slow, steady progress always wins out over short periods of despair followed by sprints of activity. It's about Joey doing her meds regularly, doing the inhalations regularly, cleaning the nebulizer regularly.

Trying to turn a negative situation into something positive is a difficult task, but it's possible. Look at what oysters can achieve. Over time, an oyster somehow manages to turn a grain of sand - an irritant - into a pearl. Of course, if you asked the oyster, he'd probably say he'd rather have the irritant removed. But since it's there, and his response is to slowly build up a coating so that the irritant no longer seems so bad. And at the end that grain of sand is turned



into a thing of beauty.

Good luck in making your own pearls!