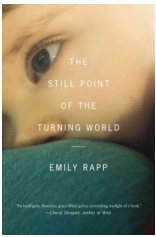


# Parenting to the Very End



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Imagine being told that your baby has a disease that will kill him, most likely before he turns three. Emily Rapp and her husband Rick were given that news when their lovely boy Ronan was only nine months old. He seemed to be having vision problems, and the eye doctor discovered cherry-red spots behind his retinas--a tell-tale sign of Tay-Sachs disease.

Emily, who had been tested for this disease, immediately knew the worst. Her husband did not. ?Well, what can we do about it?? Rick asked the doctor. ?Nothing,? was his reply. Soon the parents learned that the genetic test only checks for the nine most common mutations. So begins their journey. Emily describes in detail what it is like to parent a child that she knows will die soon. When they see the specialist, they discover that babies born with Tay-Sachs progress until they are six-months old, then start to regress, eventually losing all sight, hearing, movement, and even ability to swallow.

Emily connects to a group of mothers who have experienced firsthand this disease in their children. She dubs them ?dragon moms? because their grief is scary. It is ?primal and unwieldy and embarrasses people.? Emily becomes one of these moms.

When people ask about her son, she tells them right away that Ronan will die in the next few years. She does not mince words. After the diagnosis, some friends don?t contact her. Others jump in to do all they can to help. Particularly helpful are Emily?s exercise buddies?cycling and yoga?that she knew in California when they lived there. Emily, who now teaches writing in Santa Fe, New Mexico, guesses that since their connection was through the body, they are more comfortable dealing with physical problems. These ladies even host a Ronan-athon to raise money for the Rapp?s medical bills.

This memoir confronts the deep sadness and anger of its writer, but in it she also shares moments of deep joy, how having this horrible event happen to her, has finally taught her to live, to be totally in the moment. To enjoy the physicality of walking Ronan in his front sling up the desert mountain trail, to rub his hair, to write with him sprawled across her lap, to watch him sway in the pool with a therapist, to hear him say over and over the only word he ever learned, ?Gee.?

Throughout the book, Emily incorporates lines of poetry and sections of novels and nonfiction to help her understand?no, to help her adapt?to parenting a dying child. Most pertinent and helpful were the words of C.S. Lewis during his grief at losing his new wife to cancer.

*The Still Point of the Turning World* is not a happy-go-lucky book, but it probes the big questions: what is life, how can we survive its hardest blows, how can we parent the child we have, how can love endure and make the hardest things both possible and touched by joy.

Posted by Dory L. on June 20, 2013

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