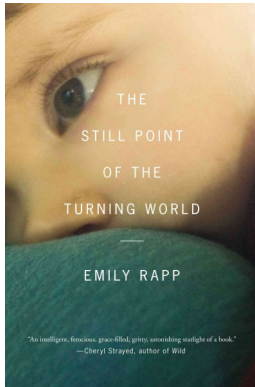


# The still point of the turning world

## 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. **[Read more »](#)**

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