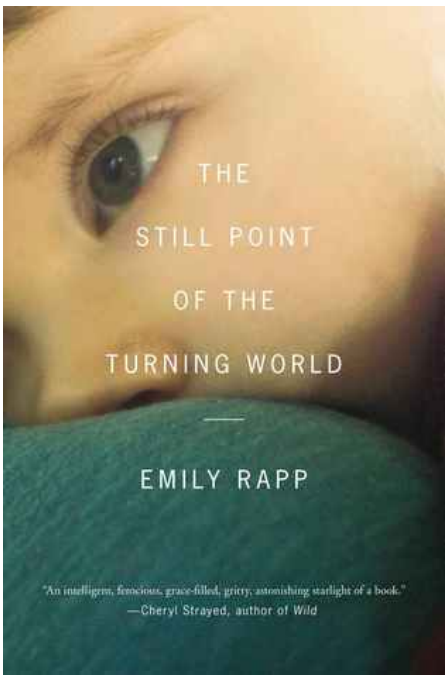

The Still Point of the Turning World

Emily Rapp

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Like all mothers, Emily Rapp had ambitious plans for her first and only child, Ronan. He would be smart, loyal, physically fearless, and level-headed, but fun. He would be good at crossword puzzles like his father. He would be an avid skier like his mother. Rapp would speak to him in foreign languages and give him the best education.

But all of these plans changed when Ronan was diagnosed at nine months old with Tay-Sachs disease, a rare and always-fatal degenerative disorder. Ronan was not expected to live beyond the age of three; he would be permanently stalled at a developmental level of six months. Rapp and her husband were forced to re-evaluate everything they thought they knew about parenting. They would have to learn to live with their child in the moment; to find happiness in the midst of sorrow; to parent without a future.

The Still Point of the Turning World is the story of a mother's journey through grief and beyond it. Rapp's response to her son's diagnosis was a belief that she needed to "make my world big"—to make sense of her family's situation through art, literature, philosophy, theology and myth. Drawing on a broad range of thinkers and writers, from C.S. Lewis to Sylvia Plath, Hegel to Mary Shelley's *Frankenstein*, Rapp learns what wisdom there is to be gained from parenting a terminally ill child. In luminous, exquisitely moving prose she re-examines our most fundamental assumptions about what it means to be a good parent, to be a success, and to live a meaningful life.

The Still Point of the Turning World Details

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From Reader Review The Still Point of the Turning World for online ebook

Corri says

I am so grateful to Emily Rapp for writing this book. Her son, Ronan, was Diagnosed with Tay-Sachs at 9-months-old in January 2011. He died in February 2013. As another who experienced the privilege and pain of her own child's "slow fade," I see this book as a gift -- to me, to my children, to everyone.

I first read Rapp's work in the 2011 NYT piece "Notes from a Dragon Mom" http://www.nytimes.com/2011/10/16/opi... and am happy that this book resonated with me as much as the article did.

This book is not the heartwrenching story of a little boy lost, it is not the bittersweet narrative of a child who will die much too young. It is not even a timeline of the trials and tribulations of parents making sense of their beloved son's short life. It is more Rapp's internal struggle to make sense of parenting, of her son's life, of her own life, of anyone's life.

I agree wholeheartedly with Rapp, who says in discussing C.S. Lewis's feelings after the death of his wife "nobody -- ever -- can feel another person's agony," so I won't say that this book describes the experiences or feelings of a parent whose child is dying. But I can say that it does describe my emotional journey.

Rapp is able to frame her thoughts in more literary and theological contexts than I do mine, but the questions for which she seeks answers, insight, and comfort are the same. I feel a kinship with her feelings on so many things: That our children were not here to teach us something -- that line of thinking does them and their own lives a disservice; that luck and fortune and even karma, if they exist at all, are not righteous; that so much of what our focus is as 21st century parents is misguided and missing the point entirely.

This book is not for the faint of heart. It is raw. Rapp writes mostly of Ronan in the past tense, but did the writing while her son was living. She includes many esoteric literary references, which I found ot be enlightening and somewhat comforting, but others may find off-putting. She discusses an experience that no one wants, and usually only want to hear about so that they can be glad it isn't theirs. But there is so much to learn about parenting all of our children from what Rapp discovers.

Gina says

As a new mother myself, I cannot imagine having a child with a terminal illness. However, the rank of two stars isn't for the author's strength of character or difficult situation (she makes clear she does't want anyone's pity anyway), or the writing, which is okay (barring that she is sometimes redundant and sometimes contradictory). She gets only two stars because of her tone. I found her to be quite self-righteous, condescending, and unappreciative. For example, she throws away all of the sympathy-type cards she receives because she doesn't like the cards' messages. We get it. Your situation totally sucks (although she also says there is no "ranking" system for difficult situations). But come on--there could have been some really heartfelt words--words she needed to hear--from the individual, if only she'd taken the time to read it. I did like that she tied in writings from other authors, and I have no doubt that she fiercely loves her son.

Josie says

I feel guilty not liking this book but I just thought it was OK. I wanted a more personal account of Ronan and his illness. And in fact I very much liked how the author spoke about her experience when I saw her on the Today Show, which is what prompted me to buy the book. But the book itself was a bit preachy and almost even pretentious to me, and more philosophical then I expected. It just wasn't a very personal account of what her life was like with Ronan and that is what I hoped for. It was a story about the author and how she used literature, writing, and philosophy to help her cope with her horrible situation. Not what I expected.

Anna says

How does one even begin to critique a memoir? I'm sure there are academic answers to this question, which rattled through me as I read **THE STILL POINT OF THE TURNING WORLD**, but I don't think any of them could help me feel less uncomfortable at the thought of making value judgements about another person's experiences and emotions. I can pick apart a novel's plot and characters with the best of them, but to do that to a memoir seems more personal. The plot, such as it is, is not of the author's creation, and the characters are for the most part outside her control. With that in mind, what more can we ask other than that she write honestly and beautifully?

In **THE STILL POINT OF THE TURNING WORLD**, Emily Rapp makes it both easy and difficult for her readers by doing just that: writing honestly and beautifully about her son Ronan, his diagnosis, and her fierce commitment to the act of mothering him while surviving her grief. Over the course of 250 pages, she explores both Ronan's short life and her role as his mother who will outlive him, and in doing so, she does an incredible job of exposing the shortcomings of how American's so frequently talk about life and death. For Ronan, ambition is non-existent; perfection, by many standards, is unattainable, yet how can we claim imperfection of someone who is, from beginning to end, no one less than exactly who he is?

> What I was being asked to do felt both entirely instinctive and completely impossible. To live the reverse of [Mary] Shelley's Dr. Frankenstein, to love my child without limits or expectations. Years from now he would not be chasing me down, asking "Why didn't you love me?" He will be dead, and I will have been his mother. It wasn't the story of motherhood I expected to tell, but...I felt I could claim it. I had to. Firefighters who spring into the blaze to save people are not brave; they have no choice. (231)

There are times when Rapp's writing is repetitive: again and again, she circles back to the things that Ronan will never do, the circumstances under which she will never mother him, the fact that her son is dying and there's nothing that will ever change that fact or her loss. Some readers may find the repetition tiresome or annoying. I experienced it as a style, Rapp's grief swirling around her like a tornado or hurricane, with stillness and clarity in the center, at the eye of the storm.

And it's in the center of her grief, as she writes about what it means to be a person, to be alive, to live with disability and difference, to be "not normal," that Rapp's contemplative writing is at its best. She has no interest in writing an overcomer narrative, an uplifting story about how her dying son taught her how to live life to the fullest, and she rejects the idea that any meaning or purpose to Ronan's existence is reliant on it

being "found" by her or anyone else.

> The meaning of Ronan's life was not to teach me; we often say this about people who defy our notions of normal and I find it pathetic, patronizing, and a way of distancing ourselves from our own fragile bodies and tenuous lives. I don't believe that disabled people exist to teach people life's stories—that is not their purpose; it isn't anyone's purpose. We are not "the disabled," some shapeless, teeming mass of nonnormative bodies designed for teaching purposes, like some kind of specially designed pedagogical barbarian horde. (114)

Emily Rapp's grief is ragged and palpable, and while her writing is beautiful throughout, there were times when I presumed to wonder why she chose to write about Ronan so immediately after his diagnosis. Some of her references to and extrapolations from various texts feel forced, and some sections seem unfocused. There's no denying that this would almost certainly have been a very different and possibly more polished book had it been written with more distance.

But then, who am I to presume to think that Emily Rapp should "polish" her grief, or that she will ever find distance—whatever that means—from the death of her son? I am a childless young adult who has lived 26 years without experiencing the death of someone close to me. I am not a professional writer, someone who instinctively turns to a blank page as a map to relief from my life. And I can't help but agree with Cheryl Strayed, whose blurb for **THE STILL POINT OF THE TURNING WORLD** reads, in part: "Emily Rapp didn't want to tell us this story. She had to. That necessity is evident in every word of this...book."

Rapp recognizes this necessity long before we ever do, and she embraces it:

> [Writing] ordered chaos, focused energy, provided a wear of "bearing up" that no period of restfulness could possible accomplish. In other words, rendering loss was a way of honoring life. ... There was nowhere to go inside Ronan's diagnosis, but on the page my mind could move, and I was for that brief period of time—an hour, four hours, three minutes, five seconds—free. (126)

THE STILL POINT OF THE TURNING WORLD is not an easy book to read—what has happened to Ronan is bullshit, plain and simple; there can be no comforting platitudes, no talk of "God's plan" or other explanations. Rapp knows that she will grieve the loss of her son for the rest of her life. At the same time, this is a rewarding book, awash with Rapp's love for her son. It's not a day by day catalogue of life with Ronan; it's an exploration of and testament to what it means to be his mother, both before and after he's died. It's meaningful and thought provoking and beautiful, and I'm glad that I read it.

February 15th via Facebook: *Ronan passed away peacefully on Thursday, Feb. 15th at about 3:30 am in Santa Fe. He was surrounded by friends and family. If you would like to make a donation in Ronan's memory, please do so at the National Tay-Sachs and Allied Diseases Association, who have been a huge support to Emily and her family.*

I received a finished copy of this book in advance of publication via The Rumpus Book Club. Subscribe to The Rumpus Book Club for $25/month and receive one new, soon-to-be released book in the mail per month, plus access to online discussions with each month's author.

Erica Nicol says

Knowing the subject matter of this book - Emily Rapp's navigation of loving and parenting her baby son Ronan, diagnosed with a terminal illness - I opened the first pages with both hunger and trepidation. The death of babies and children, perhaps because so hard to contemplate, seems to be better (or at least easier) fodder for fiction than non-fiction. We don't want these deaths to happen, after all. But they do. And The Still Point of the Turning World is a quietly gorgeous, honest and absolutely necessary book that gets to the heart of what it means to be a parent, to be human, to love deeply in the face of death.

Rapp does several things brilliantly. She brings a great deal of honesty and self-awareness to bear, sharing herself and her perspective courageously as she writes about her anger, her search for meaning and balance, her questions that never seem to be - quite - answered. She writes of her son Ronan with love and respect, and this is seen not only in her beautiful descriptions, but in her search to understand how her Ronan experiences his world, love, and his family.

But I think what endears this book to me most is the way that Rapp, as a writer and reader, turns to literature for comfort and guidance. She is a discerning and insightful reader, and when she brings the writings of writers like Simone Weil, Margaret Atwood, Mary Shelly, a wealth of poets (including Katie Ford, Kobayashi Issa, and Louise Gluck), and finally C. S. Lewis to bear on her life and that of her son, she does so brilliantly and compellingly.

Rapp's exploration of what it means to parent in the moment, without all of the future goals that commonly drive parenting, feels urgent and earnest and propels her (and her reader with her) toward wisdom. And while the subject matter of this book is as weighty as anything Atlas had to bear, her writing is not - it is deft, often wryly funny, and evocatively beautiful.

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j says

Lois McMaster Bujold, a great writer made no less great by the fact that she writes science-fiction books with covers like this, wrote one of the truest things I have ever read about becoming a parent: *“It's a transcendental act. Making life… 'By this act, I bring one death into the world.' One birth, one death, and all the pain and acts of will between.”*

This, from a story with spaceships and lasers in it.

When we have children, we birth potential into the world. We question ourselves, our spouses: who will this person be? What foods will he like? Will she be as smart as you? Will he inherit your sense of humor, your eyes, your smile? Will she be healthy? Happy? Everyone loves to tell you how your life is going to change after having kids, about how things will never be the same but also how you’ll discover a love you never imagined you could feel, filling you up and overflowing.

What they usually don’t mention is the fear. The knowledge that so many terrible things can go wrong. That the world can be a bright and beautiful place, but also a cold and hard one, and that your child will experience a measure of both. You can only hope it’s more good than bad. Only hope, and do everything you

can to make it so.

The Still Point of the Turning World is the story of a mother for whom all those fears became suddenly, crushingly immediate. Writer Emily Rapp (author of a respected memoir about growing up with a disability that requires her to wear an artificial limb) saw her future collapse in on itself one January day in 2011 when she took her infant son Ronan to the doctor for an eye exam and learned he had Tay-Sachs disease, a debilitative genetic disorder that is always fatal, that cannot be treated or cured, only managed.

Read the rest of the (slightly revised and less digressive) review on the Barnes & Noble Book Blog.

Lisa says

The Still Point of the Turning World is a memoir that will stick with me forever. Emily Rapp's story of her life with Ronan, her son who was born with Tay Sachs, is honest, beautiful, heart-breaking, full of raw emotion and poetry. I found myself slowing down to read it carefully and then going back to read sections over again. I don't usually do that. I loved the way she incorporated other literature, poems with her story. Really anything I write won't do thsi beautiful story justice. It should be on everyone's to-read- list.

Marleah says

I have an eight-month-old daughter and was afraid that, while reading this book, I would be in tears the entire time. Not so (and this is neither positive or negative, just a fact). Rapp writes about her son Ronan with love and truthfulness, with interludes into literature and references to poetry, as well as her own personal history.

While reading the first half of the book, I was irritated by the literary and poetic interludes, because just as I started to be drawn into Ronan's story and started to feel that crushing emotion, I was drawn back out with a reference to Mary Shelley or Pablo Neruda. As I continued reading, however, I realized that this book would be nearly impossible to read -- or to write -- without those interludes. The reality is simply too overwhelming and terrible to confront all at once. The interludes act as a coping mechanism, enabling one to recover before experiencing the next wave of despondency and helplessness.

Amanda says

I feel bad being at all critical of this book because the subject matter is so heartbreaking. I love the 'thesis' and message of it - that in a way it was freeing to love this child with no expectation for the future. I just wish the book would have been a little more organized. It felt very much like we were just reading a diary with no endpoint and at times it got repetitive. She is a beautiful writer though and I can't imagine how tough it must have been to write about that topic. I am glad she did.

Megan says

I was fortunate to read an ARC of this book. This book was beautiful. The author is a Wyoming native so I enjoyed reading about references to my home state. Her son, Rowan had Tay-Sachs disease. He recently passed away. She has a popular blog (Little Seal) about her journey with her son.

This book came into my hands shortly before my mother passed away. It was a serendipitous gift. It provided me such comfort as I often read it under the covers with a flashlight in my own cocoon of grief. Emily Rapp is a talented writer who is able to immerse the reader into her story without being overly sentimental or completely grief stricken. I recommend it highly. It is not just a book about loss, in fact, it is quite the opposite; it is a book about love and life.

Judith Hannan says

Toward the end of her exquisite book in response to her son Ronan's diagnosis of Tay-Sachs disease, Emily Rapp talks about going to a "Being With Dying" training session. She tells of being shown photographs of people dying and the "death portraits" of people who have just died. In many ways, The Still Portrait of the Turning World is like a death portrait; it is an unflinching examination of grief.

Tay-Sachs has no cure. Rapp makes sure the reader understands what this means in the opening pages. "I was standing on my heart, which was simultaneously beating in my nose ... I had swallowed my own teeth." Every parent whose child is diagnosed with a life-threatening illness has a view into an abyss of mammoth depth and foreigness. When my own daughter was diagnosed with cancer, I made periodic visits to that hell but I didn't have to dwell there because I had the consolation that my daughter could survive, which she did. Ronan didn't have a lilfe-threatening disease; Tay-Sachs is a murderer 100% of the time. Rapp descended into that abyss, spent enough time there to decorate it with the furnishings of innermost horrors and grief.

Against her own advise to herself and her students about waiting to achieve distance before telling a story of emotional upheaval, Rapp plunges in immediately. Writing was, "A net, a landing point, a dock from which to view the turbulent and troubled water without having to wade in it every moment of every day." But Rapp is not giving us her journal. She " ... went back and shaped [her] words ... wrestled with language and form." From her grief, Rapp has shaped a work of art as powerful as a painting, like Picasso's "Guernica."

But The Still Point of the Turning World is not an unrelenting lament. Rapp places her, her husband's, and Ronan's experience into a larger picture of how society deals with ill children or someone who is "other" (Rapp herself has a physical disability), the response of friends, etc. Sometimes these sections can seem too angry; Rapp acknowledges that she is angry and sometimes it is misplaced. She might recognize that she is too hard on the world outside her experience. Sometimes, her points become redundant and I had small quarrels with how she defined words like "lucky" or "sentimental". But Rapp's perspectives are necessary because, at some point, we will all be called upon to manage our own horror or respond to that of another, and Rapp has done the dissection for us to help us prepare.

There is no transcendence in this book, no moving forward (a phrase I hate) or even moving with (which I prefer). Rapp takes us to the threshhold across which Ronan will pass alone, without Rapp or we her readers. It is a powerful moment. I am grateful for the lack of distance in this book. How else could there a passage like this: Each day I picked apart my grief with a little knife; I combed through it; I boiled it in petri dishes

and tried to blow it up. I sprinkled it with gas and lit a match, watched it burn, put out the fire."

Rapp's love for Ronan is as physical a presence in this book as the way his body was against hers as she carried him on walks and errands, as he sat against her on the couch as she wrote. There is so much love and tenderness. There is the joy that Rapp has that she has Ronan, that she had the experience of being his mother. At our Passover seder this year, my cousin brought his three week old baby and I held him as I led family and friends through stories of freedom and liberation. Liberation is not about being unweighted but about receiving whatever weight is placed in your arms. I felt every 9.5 pounds of that baby. The thought of not carrying him constricted my muscles and my heart and I thought of Rapp.

Rapp relates her experience with such beauty, poetry, originality and both emotional and literary intelligence that, while I felt the pain of her story, I was held there by quality of the art. I can only hope that Rapp will write more.

Heidi says

Where is the line between therapeutic writing that should be contained within one's private journal, and therapeutic writing that offers meaning and perspective to a reader? Wherever it might be, Rapp stays mostly to the left of it.

I considered closing the book forever on page 36 and 47, again on page 57, and conclusively on page 123, where I read that she used to preach in her writing classes the need to achieve objectivity before sharing difficult life stories, "otherwise these stories can be heavy loads for the reader to lift."

I wish she'd heeded her own advice. She had me in the first few pages. Given the heart-wrenching subject-matter, I was pre-disposed to be hers. But now I feel as if I've been walking on my hands and knees through broken glass—not enlightened, not engaged, just confused and dizzy from all the dry redundant sermons, the circular rediscoveries of discoveries, the heavy emotional roiling that rarely seemed to cast light. The worthwhile bits, the gems and epiphanies, and I seem to think there were many of them, got lost in the vortex of what is ultimately a self-indulgent memoir of Rapp's grief and thought process.

Tracy Kidder and Richard Todd in *Good Prose: The Art of Nonfiction* say the first challenge of the memoirist is to figure out how to "preside over your own internal disorder." I wish Rapp had presided more, wallowed less. Barbara Turner-Vesselago, in her marvellous book, *Writing Without a Parachute: The Art of Freefall*, says the way to avoid the ego-involvement and ineffectiveness of writing self-consciously about recent events is to acquire a certain distance from what's being written about, say about ten years.

I didn't want to read Rapp's journal and watch her mind "spin and spin and spin." I wanted to learn from her hard-won knowledge and wisdom as she interpreted that experience, ten years hence.

Myfanwy says

Chapter 22 of Emily Rapp's memoir The Still Point of the Turning World opens with a quote from Franz Kafka, "By scribbling I run ahead of myself in order to catch myself up at the finishing post. I cannot run

away from myself.”

I cannot run away from myself.

Running away from yourself is exactly what you wish to do when you experience the dying of someone you love. And imagine if the one dying is your child? You will say to me (as people have said to Rapp), “I can’t imagine that.” But you can, Rapp would argue, and you do, which is why people like her, the mother of a dying (and now, sadly, dead) child make us so uncomfortable. They represent an inconvenient truth and that truth is that we are all of us dying as we live and that includes our children, too, though we dare not acknowledge that truth. We dare not.

Rapp had no choice but to acknowledge the truth of her son’s impending death. Indeed, she faced it head on. Still, she does not spill her tears on the page. She doesn’t ask for pity. She doesn’t want platitudes or euphemism She doesn’t want hugs. And, most certainly, she does not want anyone to say to her, “I’m sorry.”

She just wants you to be present in your life and in the lives of those you love.

Reading this book brought up all kinds of complicated emotions in me. Mostly, though, what I felt was grief: for those I’ve lost, for those I will lose someday, for myself. I grieved for Ronan. I grieved for all of the children who have died and who are dying.

Grief is not necessarily a weeping thing, as Rapp shows us within this book. What it is is an animal thing. An animal thing like giving birth. Grief is uncontrollable, as is dying, as is giving birth.

My husband and I have always talked openly (in an age-appropriate way) about death with our son. We don’t say things like “passed away” or “gone to live with the angels” no matter how tempting they are. He is interested in my parents, his maternal grandparents. I show him pictures. We talk about them. Recently, I let him take out and examine several objects of my father’s that I have. A leather box. A leather key holder.

He wrote a note (with my help) to my father asking him to leave a sign if he was a friendly ghost. He placed is in the key holder and said he would go back the next day to check. The next morning, when there was no note, he was disappointed, but said it was what he expected. He did just as I have done countless times, asking for a sign from those I have loved who have died. Show me that you still exist. Show me that there is something more.

Even as he learns of these dead people, even as he falls in love with them, he also learns how to let them go. He learns how to grieve them just as his young mind begins to understand what sad means.

Yesterday, I found two photos in frames I’d forgotten about. One was of my mother as an infant and then other of a my father as a young boy. I handed these photos to my son and told him who they were and he said, “I love them so much.”

Rob Blaine says

My enthusiasm for Still Point of the Turning World hit peaks and valleys, much as Ms. Rapp's touching story

of caring for her terminally-ill son undulates between moments of profound insight and sheer rage. But, this book epitomizes why it is I think we read books in the first place -- that search for truths through relating (or trying to relate) to the experiences of others. At least, that's why I read books, for that rare instance where a book shakes your understanding of the world and of people, and hopefully leaves you with new insights about our relationships with one another.

Bridgett says

I was about 3/4s of the way through Emily Rapp's moving memoir about her son's life and thus his dying when my daughter was diagnosed with Type 1 Diabetes. You never know exactly how much the words, the experiences, the intelligence in a book affects your own life, your own experiences, but I think I can say that ultimately this book probably changed the way I looked at the illness. Rapp's book is alive with great compassion and also an indictment of our very modern way of looking at life and death. She brings in poetry and literature in a way that is edifying and also gives the reader many reading paths to follow. I have read a lot about Buddhism lately, and Rapp's changing and moving philosophy of what it means to live more so than what it means to die has given me a better way to look at my own life and the lives of my children. I am especially moved by her discussion of value and dignity in all lives and how often we do, without realizing it, put values on lives. Like all great books, this book is beautifully written and explores a wide range of ideas, coming to rest in the liberating comfort of not knowing.
