

NEW YORK TIMES BESTSELLING  
AUTHOR OF *STILL ALICE*

# EVERY NOTE PLAYED



# LISA GENOVA

## A LETTER FROM THE AUTHOR



Dear Readers,

I'm thrilled to share my fifth novel, *EVERY NOTE PLAYED*, with you. Inspired by Richard Glatzer, the co-director of *STILL ALICE*, who died of ALS just after Julianne Moore won her Oscar, this is my most intensively researched book yet.

Like all of my books, this one starts with a neurological crisis. *EVERY NOTE PLAYED* is about ALS. While most people are familiar with those three letters in some way—maybe you dumped a bucket of ice water over your head or you saw a movie about Stephen Hawking or maybe you know someone—most people have little or no experience actually feeling what it feels like to live and die with this disease. And so in *EVERY NOTE PLAYED*, we go there.

Richard Evans is the protagonist, an accomplished concert pianist whose career ends when ALS begins in the cruelest possible way—in his hands. His ex-wife Karina, the other main character, is paralyzed in a different way—by excuses and fear, stuck in an unfulfilling life as an after-school piano teacher.

When Richard becomes increasingly paralyzed, Karina becomes his reluctant caretaker. In writing about a fatal disease with no cure, I'm looking for other places that these characters might find healing. Richard and Karina had a bad marriage followed by an acrimonious divorce. And now they're under the same roof again, in the same room, and so here is their opportunity for healing. There's so much possibility in a broken relationship—things left unsaid, apology, forgiveness, redemption. But both are holding onto a lifetime of blame and hurt, attached to being right, paralyzed emotionally, stuck in the past. Even without ALS threatening voice and breath and life, those reparative words—*I'm sorry, please forgive me, I was wrong*—can feel impossible to utter. As Richard's muscles, voice, and breath fade, both he and Karina struggle to reconcile their past before it's too late.

Neuroimaging studies have shown that brain regions responsible for thinking, feeling, and moving similar to what a character is experiencing become activated while reading. So fiction gives a way to move from sympathy to empathy. And feelings impact us as human beings far more than textbook information. I hope this book expands your awareness of ALS beyond the ice buckets, that it generates insightful discussion, that Rich-

ard's and Karina's story will inhabit you long after you read the final page.

It's been eleven years since I self-published *STILL ALICE*. Thank you for embracing these neuro-novels I write. I'm so grateful to book clubs like yours and that I no longer have to sell copies from the trunk of my car. 😊

With love and gratitude,

  
Lisa



## TOPICS & QUESTIONS FOR DISCUSSION

1. Why do you think Lisa Genova chose the title *Every Note Played* for this novel? How did the title help your reading of the novel? The original title for this book was *Diminuendo*. Why do you think she changed it?
2. Why do you think Lisa decided to make Richard an accomplished professional pianist? How does his life before his ALS diagnosis compare to life after?
3. Describe how both Richard and Karina relate to the music they played. How did music inspire them, define them, trap them, free them, save them?
4. While visiting Richard, Karina reflects on how “the story of their lives can be an entirely different genre depending on the narrator.” (p. 29). Explain this statement. How would you characterize the story of Richard and Karina’s marriage as told from Karina’s perspective? What is Richard’s point of view? Are there other instances in *Every Note Played* when two characters experience the same event completely differently based on their limited perspective? What are they?
5. Upon learning of Richard’s diagnosis, Karina pays him a visit. “She had such good intentions,” and wonders how it went “so wrong.” (p. 32). Lisa Genova wrote in her writing journal, “What is unsettled in Karina and why is seeing Richard again such a necessary risk? What does she want?” What are Karina’s motivations for visiting Richard? Did she get what she wanted?
6. Richard comes to think of Bill as “equal parts brother, doctor, parent, and friend.” (p. 96). What did you think of Bill? How does he help Richard preserve his sense of dignity, humanity, and humor? How does Bill help Karina?
7. While Richard’s ALS is progressing, he reflects on how “in a million ways, living with ALS is a practice in the art of Zen.” (p. 98). Can you think of any moments when Richard practices “the art of Zen”? What else did ALS teach him?
8. Seeing Alexander Lynch play jazz in New Orleans was a transformative experience for Karina. What changed in her? Why do you think Karina resisted going to New Orleans for so long?
9. Describe Richard’s relationship with his brothers. Were you surprised by Tommy’s apology? How does Tommy’s apology and the ensuing conversation unlock a new way for Richard to see his brothers? What does it heal?



**10.** As Richard begins to lose his voice, Dr. George suggests that Richard consider recording “legacy messages.” What are these? What does Richard think his legacy will be? Discuss legacy messages with your book club. If you were in Richard’s situation, for whom would you want to record these messages? What would your messages say?

**11.** At the clinic, the practitioners use the term care, “and Richard doesn’t openly object but care is not provided every three months when he comes for his appointment.” (p. 51). Why does Richard continue to go to the clinic? Does Richard’s opinion regarding the “care” at the clinic change? Are there different ways to provide care? What kind of care does Kathy provide to Richard? Compare and contrast this with how Bill and Karina care for him. How does Richard eventually care for Grace? For Karina?

**12.** This is very much a story about the unrelenting, progressive paralysis of Richard’s body. In what ways were Richard and Karina emotionally paralyzed? Are there ways in your own life that you’re stuck—in the past, in excuses, blame, or fear? Lisa Genova begins the book with a quote by the poet Rumi: “Why do you stay in prison when the door is so wide open?”. Why do you think she included this quote?





## A CONVERSATION WITH LISA GENOVA

**How did the experience of writing *Every Note Played* compare to your previous writing experiences? Your previous novels have been critically acclaimed *New York Times* bestsellers—did you feel added pressure while writing this one?**

I wrote this book much faster than any of my other books. Eight of the people I'd come to know with ALS died before I finished the final draft. This disease can move with alarming speed, and I think this lent a sense of urgency while I was writing, that I couldn't write fast enough. I was very much aware that many of these new friends of mine would die before they had the chance to read what they had helped me create. I penned the first draft of *Every Note Played* in less than a year, and it came out of me almost fully formed.

The only pressure comes from the sense of enormous responsibility I feel to the people living with these conditions and diseases. ALS is brutally unfair, cruelly debilitating, shockingly fast, and deadly. For the families who invited me into their lives at their most vulnerable, who shared their fears and hopes and tears and naked truths, and for every family traveling a similar journey, I want to make the best use of what they so generously gave me. I want to make them proud. I want this story to expand the world's consciousness of ALS beyond the ice buckets, to generate a compassionate awareness that contributes to better resources for care and research that leads to treatments and ultimately an end to this hideous disease.

**Many of your novels center around neurodegenerative diseases. Why did you decide to focus on ALS?**



This book began with Richard Glatzer who, along with his husband Wash Westmoreland, wrote and directed the film *Still Alice*. Richard had bulbar ALS, which means that his symptoms began in the muscles of his face and neck. That was a misconception I had about ALS. I assumed paralysis began in the lower extremities (it can but doesn't have to) and expected Richard would be in a wheelchair when I met him. He could walk perfectly at this point, but I never heard the sound of Richard's voice. He brilliantly co-directed *Still Alice* by typing with one finger on an iPad. Shortly after the film premiered at the Toronto International Film Festival, I told Richard that I wanted to write about ALS next and asked him if he would help me understand some of what he's experiencing. He was all in. We communicated by email. At this point, both of Richard's arms were

paralyzed. He wrote to me with his big toe. I am forever grateful to him for all he gave to the creation of the film *Still Alice*, for sharing with me what it feels like to live with ALS, for showing us all what grace and courage look like, for not giving up on his dreams. Richard died on March 10, 2015, shortly after Julianne Moore won the Oscar for Best Actress.

### **What other encounters have you had with people who have ALS, and how did those encounters shape the writing of *Every Note Played*?**



As with all of my books, I do intensive research. My goal is to tell the truth under the imagined circumstances, so I need to know the details in detail. This can't be done in a Google search. I came to know twelve people living with ALS, all in various stages of the disease, from less than a week after diagnosis to the day some passed away. Eight of the twelve died before I finished writing final draft. I'm honored, humbled, and forever changed by knowing all of these beautiful people and their families, grateful for every exquisitely intimate insight they shared with me. I became particularly close to Kevin Gosnell (and his family), Chris Engstrom, and Chris Connors and miss them immensely. I shadowed neurologists Dr. James Berry and Dr. Merit Cudkowicz and nurse practitioner/co-director Darlene Sawicki at the ALS Clinic at Massachusetts General Hospital; I had countless invaluable conversations and road trips to the beds and living rooms of people living with ALS; with Ron Hoffman, founder, director, and hero of Compassionate Care ALS; I interviewed Jamie and Ben Heywood who lost their brother to ALS (their family's story is profiled in the film *Too Much Too Fast* and in the book *His Brother's Keeper: A Story from the Edge of Medicine* by Jonathan Weiner); I spent time with Rob Goldstein and the amazing folks at ALS TDI; I visited Steve Saling and Patrick O'Brien at the Leonard Florence Center for Living (see Patrick's documentary *Transfatty Lives*); I learned about hospice care from Kathy Bliss and augmentative communication options from John Costello; I FaceTimed with folks who didn't live near me, as far away as British Columbia.

### **Can you tell us about your writing process? Did knowing that ALS is a terminal illness affect the way that you wrote? Were there any turns that the plot took that surprised you?**

The process for this book was similar to every book I write. I frontload with several months of pure research, and then I continue the research while writing. For more on my research and writing processes, see my blog:

[lisagenova.com/single-post/2014/04/15/Lisas-6-Rules-of-Research](http://lisagenova.com/single-post/2014/04/15/Lisas-6-Rules-of-Research)

[lisagenova.com/single-post/2014/02/19/Lisas-10-Rules-of-Writing](http://lisagenova.com/single-post/2014/02/19/Lisas-10-Rules-of-Writing)

Knowing so many people with ALS who were approaching their imminent deaths and facing it with them definitely affected the way I chose to write this novel. Although I'd touched on mortality and death in all of my previous books, death is almost an unavoidable main character in a story about ALS. There's no dancing around it. I had many candid conversations about death and dying with the people I knew with ALS, and I read many books on this topic, including *When Breath Becomes Air* by Paul Kalanithi, *Being Mortal* by Atul Gawande, *The Tibetan Book of Living and Dying* by Sogyal Rinpoche, *Awake at the Bedside* by Koshin Paley Ellison and Matt Weingast, and *How We Die* by Sherwin B. Nuland.

### **Plot turns that took you by surprise?**

I was shocked when Richard's father died. I did NOT see that coming!

### **Do you have any favorite scenes in *Every Note Played*? What are they?**

My favorite scenes were:

- The "This One Smells Like Cherries" fight between Richard and Karina
- Every scene with Bill
- The chapter with Richard's brothers



### **Both of your main characters are pianists, and you write about classical and jazz piano so fluently. In addition to neuroscience, do you have a musical background?**

I don't! I knew very little about classical and jazz piano before writing *EVERY NOTE PLAYED*, but that had to change if I was going to write about playing, hearing, and loving piano from the perspectives of these highly trained pianists with any believability. I read *Thinking in Jazz: The Infinite Art of Improvisation* by Paul Berliner, *Miles: The Autobiography* by Miles Davis, and *Journey of a Thousand Miles* by Lang Lang. I saw and heard Jeremy Denk play classical piano in Miami, Joey Alexander play jazz in Boston, and Wynton Marsalis play jazz in New Orleans. I interviewed several professional pianists, including Simon Tedeschi, Jesse Lynch, David Kuehn, and Dianne Goolkasian Rahbee. I watched many YouTube videos of pianists. My favorite is Vladimir Horowitz. And I took piano lessons! I'm still not very good, but I love playing. You can find a Spotify playlist with all of the classical pieces mentioned in *EVERY NOTE PLAYED* at my website: [LisaGenova.com](http://LisaGenova.com).

## ***How did Oliver Sacks' book *The Man Who Mistook His Wife for a Hat* propel you into studying neuroscience, and how does Sacks influence your writing now?***

I was in college, taking a course in physiological psychology, when I first read *The Man Who Mistook His Wife for a Hat*. I'd known that I wanted to be a biologist, but these two experiences sharpened my focus and ignited my passion for neuroscience. How do our brains work to allow us to think, feel, remember, desire, empathize, laugh, love, walk, and talk? I find this infinitely fascinating. Oliver Sacks wrote, "In examining disease, we gain wisdom about anatomy and physiology and biology. In examining the person with disease, we gain wisdom about life." This is what I hope I do with my writing.



## **What would you like your readers to take away from *Every Note Played*?**

Maybe prior to reading *Every Note Played*, readers read *Tuesdays with Morrie*, watched *The Theory of Everything*, or dumped buckets of ice water over their heads. They probably had some awareness of ALS. I hope they now have a deeper and more compassionate understanding of what it feels like to live and die with this disease.

Also, when people think about ALS, their first thoughts and fears focus on the horror of not being able to move or speak, on being locked in. Alongside Richard's ALS, we additionally saw the many ways he and Karina were stuck in narratives of blame, fear, and excuses, trapped in psychological and emotional prisons. Before ALS steals Richard's ability to speak, both were perfectly capable of saying anything. Their voices were physically intact. And yet, they weren't able to say what needed to be said to set each other free, to speak the needed words of apology, to offer forgiveness. I hope readers also use this story to reflect on the ways in which they might be paralyzed in their own lives, and maybe with a shift in perspective, they'll see that "the door is so wide open."

## **Are you working on anything now? Can you tell us about it?**

I'm writing a nonfiction book about memory. My next novel will be about bipolar disorder. Oh, and I'm right now re-reading the script for *Inside the O'Briens!*

## DINNER AND A MOVIE

### The Dinner

Karina brings pierogi to Richard as a peace offering, and she bakes makowiec for her family's Christmas Eve dinner. We've included recipes for each here so your book club can try them. Do you have any culinary traditions associated with the holidays? Share them with your book club. What were the pierogi an apology for? Why do you think Richard asks Karina to feed him some of the makowiec?



### MUSHROOM & SAUERKRAUT PIEROGI (Polish Dumplings):

*50 minutes total. Prep: 10 mins Cook: 40 mins*

*Yield: 40-60 Pierogi (6 servings)*

#### WHAT YOU'LL NEED

For the Sauerkraut-Mushroom Filling:

- 1 quart sauerkraut (chopped, rinsed & drained)
- 2 tablespoons butter
- 1 small onion (finely chopped)
- 8 ounces button mushrooms (finely chopped)
- ¼ teaspoon salt (or to taste, remembering that the kraut is salty)
- ¼ teaspoon black pepper
- Optional: 1 egg (hard-cooked, finely chopped)
- 2 tablespoons sour cream

For the pierogi dough:

- 2 large eggs
- 5 tablespoons sour cream
- 3 tablespoons vegetable oil
- 1 teaspoon salt
- ¾ cup chicken broth
- 4 cups all-purpose flour



#### HOW TO MAKE IT

Make the Filling:

Place sauerkraut in a medium saucepan and cover with water. Bring to a boil, reduce heat, and simmer for 20 minutes. Drain.

In a large skillet, sauté onion in butter until golden. Add mushrooms and

sauté 3 minutes. Stir in sauerkraut, salt, and pepper. Sauté until kraut turns golden, about 20 minutes. Remove from heat and let cool.

Add chopped hard-cooked egg (if using) and sour cream (you might need less sour cream if you don't use the egg or more sour cream if you do use the egg) and mix well. The consistency should be like a paste. You should be able to form it into a ball.



Make the pierogi dough:

In a large bowl, combine eggs, sour cream, oil, salt, and chicken broth until well mixed.

Add flour and knead by hand or in a stand mixer until the dough is smooth. Wrap with plastic and let rest at least 10 minutes.

Fill and Cook:

Using a 1 ½ inch cookie scoop, follow these steps to roll, cut, fill, and cook pierogi

Roll out the pierogi dough: on a lightly floured, surface roll out the dough to a ¼ inch thickness.

Cut the pierogi dough into circles: using a 3-inch round cutter, cut the dough. Gather scraps, cover with plastic wrap and set aside.

Fill the pierogi dough circles: using a 1 ½ inch cookie scoop, portion your filling on all of the dough circles before folding.

Seal the pierogi dough with clean, dry hands, fold dough over filling to create a half-moon shape. Press edges together, sealing and crimping with your fingers (or use a fork) as for a pie. *If your dough is dry, moisten edges with egg wash (1 beaten egg with 1 teaspoon water) before pressing edges together.*

Roll, cut, and fill reserved scraps.

Bring a deep pot of salted water to a boil.

Reduce to a simmer and drop 12 pierogi at a time into the water. Stir once so they don't stick to the bottom.

When they rise to the surface, cook 3 minutes or until dough is done to your liking.

Remove with a slotted spoon to a platter that has been smeared with butter.

Repeat until all pierogi are cooked. Serve with melted butter, or sauté in melted butter until golden brown (see below).



### How to Fry Pierogi:

Pierogi can be fried after boiling if desired. Add 1 stick of butter to a heavy, large skillet, and fry pierogi on both sides until lightly browned



## **MAKOWIEC (Polish Poppy-Seed Cake):**

*Ready in 1 hour, 50 minutes. Yield: 1 Cake, serves 16*

### **WHAT YOU'LL NEED**

For the dough:

4 teaspoons active dry yeast  
1 tablespoon sugar  
1 pinch of salt  
1 cup milk, warmed  
3 cups flour  
1 egg  
1 egg yolk  
4 teaspoons vanilla extract  
4 tablespoons butter, melted

For the filling:

½ lb poppy seeds, rinsed  
½ cup sugar  
4 tablespoons butter  
¼ cup raisins  
¾ cup almonds, ground  
¼ teaspoon vanilla extract  
4 tablespoons honey  
1 egg white  
1 egg white, lightly beaten

### **HOW TO MAKE IT**

For the dough:

Mix together yeast, sugar, and salt in a large bowl.

Pour in milk, stir until dissolved.

Whisk in 1 cup of flour, cover, and let rise in a warm place until doubled, about 15 minutes.

Stir in egg, egg yolk, and vanilla extract.



Knead remaining 2 cups flour and butter into yeast mixture, adding each alternately a little at a time.

Knead until smooth and elastic, about 15 minutes.

Place the dough in a large bowl, cover, and let rise until doubled, about 1 hour.

For the filling:

Simmer poppy seeds in a medium pot full of water until soft, about 40 minutes.

Drain and purée in a food processor, about 4 minutes.

Return poppy seed puree to same sauce pan.

Add sugar, butter, raisins, almonds, vanilla extract, and honey.



Cook, stirring, over medium-low heat for 15 minutes.

Set aside to cool.

To cook:

Preheat oven to 350 degrees Fahrenheit.

Roll out dough to a 16" x 12" rectangle.

Whisk egg white in a bowl into stiff peaks, fold into the poppy seed filling.

Spread over dough, leaving a 1" border all around.

Fold dough lengthwise in thirds to form a long log.

Pinch ends to seal.

Place cake on nonstick baking sheet, brush with beaten egg white, and bake until it sounds hollow when tapped, about 50 minutes.

Cool before serving.



## The Movies

### *Too Much, Too Fast*

This was the first documentary about ALS that I watched. An inspirational and heartbreaking story about architect/builder Stephen Heywood, diagnosed with ALS at age twenty-nine, and his brilliant brother Jamie, who became obsessively driven to find a cure. I fell in love with the Heywoods. I wanted to be part of their family and Jamie's renegade quest.

Jamie founded ALS Therapy Development Institute (ALS TDI), the world's first nonprofit biotechnology company, a place I came to know well while writing *EVERY NOTE PLAYED*. I met with Jamie and Stephen's other brother, Ben, in doing the research for my book. They shared the brutality and intimacy, the reality and the hope in loving someone with ALS. If, like me, you can't get enough of these brothers, Jonathan Weiner pens their story in *His Brother's Keeper*. Stephen died in 2006.



### *Imber's Left Hand*

I LOVED this documentary about artist Jon Imber. As ALS paralyzes his right hand, he learns to paint with his left, and then with both hands held together at his waist. He painted more than 100 portraits in 4 months like this. His determination to keep painting, to keep seeing, to keep loving and growing in the presence of crippling physical demise is awe-inspiring and heroic. His wife Jill said, "What you do at the end of your life is an interesting doorway." Wow.



### *The Theory of Everything*

I saw this movie about theoretical physicist Stephen Hawking about a week before the Golden Globes in 2015. I was mesmerized by Eddie Redmayne's portrayal of Hawking with ALS, how he embodied the changes in physicality that accompany increasing paralysis with such authenticity and believability. A few days later and the night before the Golden Globes, I attended a swanky party for *Still Alice* in Beverly Hills. Before walking through the front door, I told myself to *be cool*. But the first person I met was Eddie, and *cool* laughed at me as it flew right out the window. I gushed all over him. I was horrified with myself as I was gushing but couldn't stop myself. When I was done vomiting compli-

ments, Eddie very graciously thanked me and asked, “Who are you?” I unassumingly answered, “Lisa Genova. I wrote *Still Alice*.” And then, Eddie Redmayne gushed all over me. 😊 PS. The next day, Eddie won Best Actor. #TrueStory #MindBlown

### *Transfatty Lives*

Patrick O’Brien (not Katie’s older brother in *Inside the O’Briens*) was DJ Transfatty and a filmmaker, thirty years old and living in NYC when he was diagnosed with ALS. He turned the camera on himself, making this extraordinary, darkly humorous, thought-provoking, and inspiring documentary about his journey. “What if my diminishing physical abilities can be inversely proportional to my journey inward? And, more importantly, will there be bacon and unicorns once I get there?” I met Patrick at the Leonard Florence Center for Living in Chelsea, MA where he now lives—unable to walk, talk, or breathe, his creative mind still alive and well, typing with his pupils.



### *Gleason*

This documentary about former New Orleans Saints safety Steve Gleason stirred many big emotions in me. Shot with handheld cameras, this film gets up close and personal, yanking back the curtain, exposing an extremely intimate view of the realities of living with ALS. Both Steve and his wife Michel are amazing, beautiful human beings, determined to live and love with courage and purpose. While Steve is portrayed as a “no white flags” heroic public figure, and he is, I found Michel to be the real hero of their story. My heart broke hard and in many places for her, and I have wondered and worried about her often since seeing this film. Caregivers will definitely identify with her. With his eyes, Steve wrote, “I cannot move or talk or breathe on my own, but because of evolving eye-tracking technology, which I use in conjunction with a tablet, I can do anything an ordinary person can do: text, talk, play music, watch movies, conduct online meetings...” And he can do these things because Michel and other caregivers devote their time, energy, and love to washing, dressing, toileting, and feeding him.

*It's Not Yet Dark*

This film was released after I finished the final draft of *EVERY NOTE PLAYED*. Narrated by Colin Farrell, *IT'S NOT YET DARK* reveals the story of Irish filmmaker Simon Fitzmaurice who was diagnosed with ALS at the age of thirty-four. It's an intimate portrayal of a young family hurled into the unthinkable and unexpected crisis of ALS. Simon's steadfast and optimistic determination to live, to not give up on love or his dreams is inspiring and uplifting. Because ALS never happens to just one person, this is also the story of Simon's wife, Ruth. As I watched her take care of him and their five young children, I kept wondering what she wanted, what her dreams were. We don't see either of them ask or answer those questions. Arms, legs, breath, and voice paralyzed, Simon amazingly continued to live a productive and meaningful life, writing the book upon which this film is based and directing his first feature film through eye-gaze technology. He died in October 2017.



## The Music

Listen to Maurice Ravel's Piano "Concerto for the Left Hand" with your book club. Did you enjoy it? Why is this musical composition particularly meaningful to Richard? Are there any musical compositions that hold a special place in your heart? What are they?

*Read along with this playlist to listen to the classical pieces described in Every Note Played:*

<https://open.spotify.com/embed/user/gallerybooks/playlist/3xBglbpMjH-Q1B2zsyeKfa>

To learn more about Lisa Genova, read more about her other books, and find out when she will be in a city near you, visit her official site at [www.LisaGenova.com](http://www.LisaGenova.com).





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