

Bioethics Book Club



Every Note Played

By Lisa Genova

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Summary¹

Richard is an accomplished concert pianist, who has toured the world and received recognition for his skills worldwide. He has now been diagnosed with ALS, and are no longer able to play piano because his entire right arm is paralyzed. Richard divorced Karina three years earlier. Together they have a daughter, Grace, who have moved away from home to go to the University. Karina and Richard does not get on after the divorce. Karina feel stuck in an unfulfilling life as a piano teacher, after she abandoned the path to become an accomplished jazz pianist. She is bitter and blame Richard, and their failed marriage for all of it.

Richard's illness is progressing fast, but he is hesitant to accept it and does not immediately follow advice from his therapists. When he becomes increasingly paralyzed and it no longer able to live on his own, Karina reluctantly offers to become his caretaker. As his ALS progresses the little family try to reconcile their past before it's too late.

Ethical Issues

Living at risk

Dignity

Hope

Advance care planning

End-of-life

Burn-out

Discussion questions:

- Richard choses to do things that puts him at risk (i.e. going to the park and eating solid food). What concerns would you have around intervening or not intervening with a patient's choice to engage in activities that puts them at risk?
- "Bill and the other home health aides from Caring Health, his physical therapist, Kathy DeVillo, and his neurologist all told them, warned them, practically begged them to build the ramp sooner rather than later. Don't wait. They both blew it off." (Page 248). Why do

¹ Adapted from publisher's summary.

you think Karina and Richard didn't take the advice from Richard's health care providers to be better prepared for the progression in his illness? In your experience, is this a common reaction from patients and families?

- What did you think of Dr. George's advice to Richard about recording legacy messages?
- Why do you think Karina decides to offer Richard to move in with her and becoming his caregiver?
- What was your reaction to the Richard and Karina delaying telling Grace about Richard's illness?
- How does Richard's caregiver, Bill, help Richard preserve his sense of dignity?

Discuss the following passages from the book:

Page 52: Kathy is the nurse-practitioner overseeing his medical care at the ALS clinic. Care is the term they use here, and Richard doesn't openly object, but care is not what's provided every three months when he comes for his appointment." [...] There clinic visits primarily amount to data collection, a chronicling of worsening symptoms indicative of disease progression."

Page 62. "He's going to lose Ravel's Piano Concerto for the Left hand. He'll never play piano again. This is the loss he's imagined in microscopic detail from the first hints of this disease, the one that guts him through his center and keeps him from sleeping and makes him want to swallow a bottle of pills and end his life now. Because without the piano, how can he live? Yet, this isn't the loss that has him suddenly stunned and panic-stricken, unable to swallow his own pooling saliva. [...] He's about to lose his left arm. Three month ago, he hugged Maxine for the last time. Could that be the last embrace of his entire life?"

Page 149-150. "He clears that bite and asks for another. As he chews, he looks into Karina's unwavering green eyes, and the cruel awkwardness and pity he dreaded in being fed by her in particular isn't there. Instead, a gentle intimacy, a quiet tenderness passes between them that he never expected. After the next bite, she wipes his bottom lip with a napkin, and he feels appreciative instead of ashamed."

Page 164. "Sweetheart, forgiving Richard is for you. Not for him." She softens her stance, surprised to be considering this perspective. [...] Bill look her straight in the eye, making sure his words landed, and her heart beats faster as if it's been warned or dared or threatened. She nods but has no idea yet what she's agreeing to."

Page 249: "Richard truly believe he might never need the damn chair: [...] "Sitting in his wheelchair, staring at the floor unable to leave the house, it's clear now. No part of him is safe room this disease."

Page 248: "The activation energy is a mountain precipice – too many insurance forms, the astronomical cost despite any coverage, the wait to receive the device."