

**EMBRACING MORTALITY: A JOURNEY OF ACCEPTANCE AND LIFE
REFLECTION IN LISA GENOVA'S *EVERY NOTE PLAYED***

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ABSTRACT:

The mortal nature of the living beings has always been concept that is a hair splitter to every human beings who have lived and are living on this earth. The inevitable nature of mortality does not actually prepare them to face it but morbidity puts a pause in an individual's life to reflect and accept their life as it is. The periods of diagnosis, denial, life reflection and acceptance hold their own significance in preparing a person towards the acceptance of the mortality. Richard Evans, the protagonist of the novel *Every Note Played* by Lisa Genova is a renowned pianist who is diagnosed with ALS. This morbid disease with no cure forces Richard to look back and reflect on his life and prepare him to face his end. This paper attempts to explore the crucial steps of the protagonist in his journey with the disease and the impact it created in his life after the diagnosis.

KEYWORDS: Morbidity, ALS, Denial, Acceptance, Mortality

INTRODUCTION:

Lisa Genova is an American author who began her career as a neuroscientist. She has a Bachelor of Science degree in Biopsychology and graduated from the Bates College. She was awarded with a doctorate for her research in neuroscience by the Harvard University. She was interested in the research of the brain related disorders and also taught neuroanatomy. Lisa Genova published her debut novel *Still Alice* in 2007 which is about the struggles of a renowned cognitive and linguistics professor of Harvard University diagnosed with early onset Alzheimer's. The next novel, *Left Neglected* published in the year 2011 is about the struggle of a woman affected with a rare condition called Left Neglect as a result of the brain injury caused in a car accident. The third novel *Love Anthony* published in the year 2012 is about the life of a boy with autism. In 2015, her next novel *Inside the O'Briens* was published. It is about a policeman diagnosed with Huntington's disease and the members of the family who have inherited the disease. The following novel, *Every Note Played* was published in the year 2018, discusses the life of a pianist who was diagnosed with ALS. She has also published a non-fiction titled *Remember: The Science of Memory and the Art of Forgetting* in 2021 which is a bestseller according to The New York Times Best Seller list.

The themes of the novels written by Lisa Genova include awareness on neurological conditions such as Alzheimer's, Huntington's and ALS, These diseases have no known causes and have 50-50 chances of being passed on to the next generation. They also occur in individuals without the genetic history. Left Neglect, also known as hemispatial neglect is caused due to the traumatic brain injury or stroke in the right side of the brain leaving the patients with difficulty in acknowledging or paying attention to anything that is present on their left side. The novels deal with the sick people, their view of the illness, the changes brought into their lifestyle. The shift in the individual's perception of the world and the impact it creates on their identity. They also focus on the strain of the illness on the family and caregivers and on the whole the novels aim to create an understanding of the disease and awareness to the readers.

ACCEPTANCE OF MORTALITY AND LIFE REFLECTION

Morbidity refers to the situation where an individual is not in a healthy condition due to a particular disease. Mortality refers to the rate of death caused due to a particular disease in a particular group of people or the whole population. Mortality is also describes the mortal nature

of a living being. The mortal nature of the humans doesn't bother them until they are interrupted by any events or diagnosis that forces them to consciously think of their death. The fear of death leads to denial and delays the individual from processing and accepting the diagnosis.

Richard Evans is a famous pianist who performs in all the world renowned stages where he is showered with utmost appreciation and love. He is so efficient and effortlessly meticulous in playing the masterpieces of musical stalwarts like Chopin, Bach, Schumann, etc. He is at the peak of his career, shining bright in the limelight when he is diagnosed with Lou Gehrig's disease also known as ALS- Amyotrophic Lateral Sclerosis. It is a neurodegenerative disease that causes the degeneration of motor neurons that are responsible for the voluntary movement of muscles ultimately leading to complete loss of control over the muscles. The person diagnosed with this disease experiences progressive symptoms of loss of ability to movement, eat, speak and breathe, branding it a terminal disease.

The diagnosis leaves Richard shattered and lonely, forcing him to hide out in his condo in Boston. His agent Trevor sends out an official press release cancelling all his tours stating tendinitis. Richard thinks that his agent is in denial when he was diagnosed with ALS but even after six months, Richard has a hard time to accept his diagnosis as he experiences no symptoms during parts of a day. He even thinks of a possible wrong diagnosis hoping the symptoms are due to some other underlying issues. "It is virus. A pinched nerve. Lyme disease. Tendinitis. A temporary problem, and now it's resolved. Nothing's wrong." (19)

Richard experiences fluttering seizures, twitching and spasms in his muscles which he is able to feel across his whole body. He lies very still to let the episode pass through and sometimes for hours together. Richard is deep in contemplation thinking about the possibility of losing the ability to feel any sensation in his body very soon. He is deeply moved to be grateful for being able to feel the twitching which indicates the responding ability of the muscles. Richard is aware of the fight against this unknown enemy and considers the twitching of the muscles as a silent cry for help. "Every twitch is a muscle stammering, gasping, begging to be saved. They can't be saved." (22) Richard tries to picture the twitches which are similar to his car's blinking fuel light that warns the driver of the low gas. He tries to calculate the time left for him to be completely bed ridden like a car engine that comes to a complete halt once out of gas.

Gradually, Richard starts to lose his right fingers, arm and hand to ALS. He is devastated to find his right hand paralyzed, unable to play with the keys of his piano. Soon panic takes over him and he plays the Brahms I notes with his left hand and the right hand notes in his mind. The transcendental music calm him down. “While playing solely with his left hand, he closes his eyes to lose sight of his immovable corpse hand, and this cut-and-paste, mind-body performance is satisfying to him for a bit.” (35) Richard has developed the habit of self-examination, a daily ritual to ensure if he still has movement in the rest of the body except for his right hand, which he considered to be more essential than his heart beat. He is still in some sort of denial, believing he still had control over the progression of this uncontrollable disease.

Richard visits Kathy DeVillo, a nurse-practitioner at the ALS clinic every three months to record the progression of the disease and to review and adjust the dosage or change or add medications to tackle the progressing disease. During one of his visits, Richard realizes the progression of symptoms in his left hand and is overcome by fear of losing his only chance of playing the piano, which had been his only source of comfort. He is even more dreaded by the fact that he could no longer hug anyone or feel the embrace which he had experienced three months ago when his girlfriend Maxine had left him. Desperate to feel the human connection, Richard asks for a hug with tears down his cheek. “He hugs her with his left arm, pressing her into him, and she responds, hugging him back, and their contact creates a human connection that feels vital to him as the air he can still breathe.” (63) As the disease progresses and takes away his left hand too, Richard is forced to rely on house aides for all his basic necessities like using the washroom, bathing, dressing, grooming, eating food, etc. Bill is the morning aide who helps in his basic needs and settles him in front of the television, prepares his breakfast as smoothies and leaves. Melanie is another aide who prepares his lunch. Bill comes again in the evening to help him with his dinner and settles him in his bed.

An unfortunate event forces Richard to move back to his ex-wife Karina’s house, whose earlier efforts to connect did not end well. Richard and Karina’s daughter Grace has not been in close touch with her father after their divorce owing to Richard’s history of cheating. Realizing that he hadn’t been a good father to Grace, Richard hesitates to disclose his diagnosis to Grace and it comes as a surprise to her when she comes home for holidays. Grace is not able to face him and Richard struggling with guilt, remembers his own childhood being neglected by his

father for loving the piano and not the sports like his brothers. Richard is finally at peace with his past at his father's funeral where his brothers apologize for not standing up for him. He forgives them and is free from the burden he had been carrying for a long time.

Richard absorbs the acceptance and apology given to him by his brothers, and a space begins clearing inside of him, a field stretched to the horizon, a morning sky, a universe of stars. Still overwhelmed and unable to speak, he silently thanks his brothers, one generation healing the wounds inflicted by another. (222)

Richard feels as if he had failed his own daughter just like his father did to him and now he feels ready to apologize. However all his attempts fail, until one night Grace finds him collapsed on the floor, he apologizes to her. "He's sorry he didn't give enough of his time to her. He's sorry he's running out of it. He's afraid he doesn't have much left. He's sorry he wasn't a better father to her. He's sorry she didn't feel loved by him" (234). Richard is able to apologize to his daughter, which he as a son expected a long time from his father. Grace lets out her tears which symbolizes forgiveness for her dad and her love for him.

Richard being confined to bed is able to listen to Karina playing the piano and looks back to their college days when she left classical piano for jazz music. Karina was more talented than Richard and praised by all the professors. Richard couldn't appreciate her back then and robbed her of her chance to become great in jazz when he relocated them to Boston with a purely selfish motive. Even after moving back to Karina's home and receiving all the help from her, he couldn't appreciate her though he feels grateful. But slowly he realizes the need for reconciliation as his breathing gets worse and he is in need of the assist of a BiPAP machine to breathe better. Looking at her being tired with dull eyes and feels, "He wants to tell her that he's sorry that she's so tired. He's sorry that he has this and had nowhere else to go. He's sorry that he's become such a burden to her. And then suddenly, strangely, for the first time he wants to tell her that he's sorry for all of it" (158).

Towards the end of the novel, Richard is rushed to the hospital and intubated. He is offered with a choice to go on life support or go off the ventilator support. Though he had been preparing for this moment, he still feels unprepared to face his end. The next day morning he decides to wean off the ventilator and is taken home under hospice care. Richard makes a final apology to Karina through a music piece and Karina also apologizes for not giving him the

family he desired and being the woman he loved. Richard slowly passes into the oblivion knowing that he had been forgiven and set Karina free from her guilt so that she can move on and live her life from now on. He reiterates this message through his final legacy note left in his voice recorder which is received after his death giving hope to Karina.

CONCLUSION

Emily Dickinson in her poem *Because I Could Not Stop For Death*, “Because I could not stop for Death —/He kindly stopped for me—” (Dickinson, lines 1-2) says that the speaker of the poem was not ready for death. It was death who came to the speaker who had no previous news about the visit from death. The speaker is taken on a journey through various places giving the speaker a chance to reflect on his/her life before reaching the final resting place. Likewise the protagonist with the terminal illness awaiting death is able to look back, reflect on his life and finally accept his death. Death is a part of each and every living being on this earth and human beings are not an exception to this. They are very much aware of this yet a diagnosis of incurable disease tumbles the balance of an individual. Richard who initially was in denial is hopeful for a miracle cure or a halt in the progression of the symptoms. As he retrospect his life, he is able to apologize, heal and forgive himself and others who were the significant part of his life. This gives him the peace and free him from the fear of the approaching death.

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