

Alzheimer's: "Angst" and "Identity Crisis" in Lisa Genova's *Still Alice*

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"Old age is second childhood, mere oblivion, sans teeth, sans eyes, sans taste, sans everything."

- As You Like It

Alzheimer's disease and the cumulative trauma associated with the disease are featured in popular media like movies, fiction and plays in various ways. On the one hand, physicians keep updating definitions regarding the disease and on the other, literature portrays such diseases in various dimensions. This paper analyses Lisa Genova's novel Still Alice and dwells at length with the complications faced by Alice Howland, a Professor in Linguistics at Columbia, who is diagnosed with Alzheimer's disease (henceforth referred to as AD). The paper also explores into the various attempts of Genova to prove that AD patients have a great desire to express their feelings. Just because they lack words to translate their emotions into meaningful conversation, it doesn't mean that they are a bundle of flesh and bones that can only digest food and excrete waste. The novel shows how the protagonist, Alice reconstructs her 'self' and identity amidst her immense psychological and physical constraints. The success of the novel lies in the portrayal of the trauma in a telling manner, from the point of view of the victim. Lisa Genova's portrayal of the plight is a record of the unheard sorrows of the victims of AD and she voices their sufferings thereby allowing space for the readers to enter and explore into their silent world.

The sense of loss and attempts of reassertion

Alice realizes that she has memory loss initially when she finds it difficult to land at the word "lexicon" in a lecture. She receives with shock, the message from Dr. Davis that she has early onset of Alzheimer's disease. The shock vibrates through her body:

"Alice" (79)

"The sound of her name penetrated every cell and seemed to scatter her molecules beyond the boundaries of her own skin. She watched herself from the corner of the room." (ibid)

Genova consciously dramatizes the events and makes Alice an observer of her own destiny. There are sufficient markers in the discourse that allow room to justify the notion that Alice takes control of her situation from an observer's point of view, so that she can take firm decisions. After Alice utters every word, she confirms that she is doing it right: "She hears herself ask," "She hears herself say" and "She sees herself nod." In medical discourse, AD is a "progressive degenerative disease of the brain" and it is widely believed that AD victims are affected by cognitive and functional deficits, as well as behavioral and affective disturbances. Genova uses an alternative discourse, a narrative technology with a dramatizing effect in which the actor is her own audience, in order to ensure that Alice is doubly sure of what is happening and the way she responds to it.

Alice understands the consequences of her disease and she accepts living with it. She, in fact does not in any way relate herself to the usual, negative attributes of AD patients. Alice in fact becomes aware of her body in a way that she had never done before. When she sits on the cold steel chair as she waits for the doctor to give his affirmation regarding her condition,

She became strangely aware of hands clenching the cold metal arms of the chair she sat in. *Her hands*. She hadn't become an ethereal collection of molecules in the corner of the room. She, Alice Howland, was

sitting on a cold, hard chair next to an empty chair in a neurologist's office in the Memory Disorders Unit...." (80-81)

Alice begins realizing her 'self' more after she is diagnosed with AD. She never in any occasion displays dismay or collapse of her senses. She does not seem to fall out of time or space. She feels alienated and humiliated only due to external forces. This shows that the sense of loss of AD patients experience is not inherent or a resultant attribute of the disease. It is due to the negligence and humiliation that others put them to.

When Alice reads the form to be filled in by John, her husband, the word, "informant" disturbs her: "The word informant, the closed door, and her pounding heart all contributed to a feeling of conspicuous guilt, like she was hiding in some Eastern European city, in possession of illegal documents, and the police were on their sirens blaring." (81) Hence the sense of loss that descends upon her is not when she is diagnosed with Alzheimer's disease, but when she is pushed from main stream and made a dependent survivor. She feels humiliated when she reads the form that rates the patients: "Number 3 was a humiliating list: Must be fed most foods. Has no control over bowel or bladder. Must be given medication by others. Resists efforts of caretaker to clean or groom. No longer works. Home or hospital bound." (81-82) Alice is intelligent enough to reason out, "Were the eighty year olds incontinent because they had Alzheimer's or because they had eighty year old bladders?" She feels that it would all suit for an old person, but not to "someone like her, someone so young and physically fit." (82) This confidence in her pushes her forward and she tries her level best to sustain her sanity and intellect, if not overcome the disease.

Loss of words: Loss of World

Alice's sense of loss is due to her loss of language. As the disease progresses, Alice's sense of loss and identity is mainly due to her loss of language. She becomes confused when, talking to others. She is unsure of the message or context while she reads something. It is more difficult when it comes to telephone conversations: "Words sometimes ran together, abrupt changes in topic were difficult for her to anticipate and follow, and her comprehension suffered." (106) Earlier, when she reads the Activities of Daily living Questionnaire, Alice checks the questions related to communication and feels more than depressed. "The worst part of it came under the heading, 'Communications.' Speech is almost unintelligible. Does not understand what people are saying. Has given up reading. Never writes. *No more language.*" (82) Alice thinks of the long list of books she had wanted to read, the list of periodicals waiting for her articles, the bundles of answer scripts to be evaluated and the lectures that she had to deliver. For her language and communication are everything and without it. she wouldn't be Alice at all. "Everything she did and loved, everything she was, required language." (ibid)

Alice feels perturbed by the questionnaire and she feels tempted to fill it out herself and prove Dr. Davis wrong. She is so confident in that moment, but she is also conscious of the fact that her memory will decline and she won't be the most reliable person to narrate what is happening in her life. She arrives at the most pathetic realization that someday, "... she'd look at her husband, her children, her colleagues and faces she had known forever, and she wouldn't recognize them." (83) This understanding of Alice brings in the sympathy of the readers, has something rational, intellectual and a sort of preparedness attached to it. And she takes every step to improve her condition so that she does not become a burden to her family.

Connecting with Words: Connecting with the Glorious Past

Genova portrays many situations in which Alice gets connected with her past, as an attempt to re-ascertain her identity. In one scene, Alice once opens the folder "butterfly" on her desktop and comes across a letter once she once wrote to herself. The letter dwells at length on her beautiful life and amazing academic career at Harvard. The letter contains instructions to commit suicide: "This last part, the part with Alzheimer's and this end that you've carefully chosen, is tragic, but you did not live a tragic life. I love you, and I'm proud of you, of how you've lived and all that you'd done while you could." (303) The letter is a bridge between her present oblivion and her glorious past. "She read it again. It was fascinating and surreal, like reading a diary that had been hers when she was a teenager, secret and heartfelt words written by a girl she only vaguely remembered. She wished she had written more." (304)

In another instance, Alice get connects with her past of intellectual eminence as she reads through the pages of a thick blue book "disinhibition, phosphorylation, genes, acetylcholine, priming, transience, demons, morphemes,

morphological." (317) The words appeared to her like faint imprints on a glass plate, still pristine in a corner of her brain and mind:

This thick book with its shiny blue cover represented so much of what she used to be. *I used to know how the mind handled language, and I could communicate what I knew. I used to be someone who knew a lot. No one asks for my opinion or advice anymore. I miss that. I used to be curious and independent and confident. I miss that. I miss being sure of things. There's no peace in being unsure of everything all the time. I miss doing everything easily. I miss being part of what's happening. I miss feeling wanted. I miss my life and my family. I loved my life and family.* (318)

The sense of loss due to loss of language and memory is more painful when Alice remembers her glorious past and she misses all that she had in her past. She laments: "I miss myself." And so does John: "I miss you, too, Ali, so much." (320)

During a commencement, at Harvard, Alice meets Dan who was graduating. Dan is full of gratitude and praise for Alice: "Your passion for understanding how language works, your rigorous and collaborative approach to research, your love of teaching, you've inspired me in so many ways.... You've been the best teacher I've ever had. If I achieve in my life a fraction of what you've accomplished in yours, I'll consider my life a success." (310) Even if Alice succumbs to the disease slowly at the end, it is not that she had never had a glimpse of her glorious past. For an AD victim, a journey to the past is a million mile journey. To travel through such a glorious past, brushing aside the entangled weeds of memory is a Himalayan task. The effort to reminisce such wonderful events is an attempt by Alice to re-ascertain her lost identity and 'self'.

Identity Crisis and Family Members

Alice doesn't want to hand over the responsibilities of the questionnaire to John because, "If she confessed to John what Dr. Davis had told her, if she gave him her Activities of Daily Living questionnaire, it would all become real. John would become the informant, and Alice would become the dying, incompetent patient. She wasn't ready to turn herself in. Not yet." (84)

We see Alice to be more practical and determined than her family members. When she announces that she has AD, John is reluctant to accept the fact and keeps arguing and reading more on it. His love for Alice is deep and he would never like to watch her taking her pills to fend off her illness. Anna, her daughter, initially feels annoyed because of the chances that she might inherit the disease and that her child might also. She is alarmed that she too might roam around like a 'mindless zombie.' But later she understands the situation and takes care of her mom. Often family members deal with AD victims un-empathetically. They fail or forget that AD victims are listening and that they often understand what is being discussed. When the whole family discuss issues pertaining to Alice, she feels deprived of not letting her participate in the conversation or not asking for her opinion, in matters that relate to her: "They talked about her as if she weren't sitting in the wing chair, a few feet away. They talked about her, in front of her, as if she were deaf. They talked about her, without including her, as if she had Alzheimer's disease." (251) There are two aspects to be discussed in this situation. Firstly, the exclusion that Alice suffers makes her feel that people treat her as if she was 'deaf'. But when she realizes that her presence or absence is not a matter of concern to her family members in discussions pertaining to her, she feels that she is degraded and pushed to a state of mere 'existence' from that of 'living'.

When Alice reads John's instruction, "DO NOT GO RUNNING WITHOUT ME," (231) she feels like screaming that she doesn't need a baby sitter and that she can manage herself. But she controls her emotions, congratulating herself for having "editorial control over raw emotions." (ibid) While this is her experience with other family members, Alice's attitude towards her third child is very peculiar. She recognizes her in "pieces, close up shots of features." (257) "But strangely, she had a hard time in identifying Lydia as a whole." (ibid) She fears that she might not be able to recognize her beautiful child at all some day. But Alice feels convinced that "the mother in her believed that the love she had for her daughter was safe from the mayhem in her mind, because it lived in her heart." (258) Alice knows that John loves her deeply. But she also realizes that she had always made things easier for him. She admires John's passion for research and secretly wished that she could be his passion, so that he would spend all his time with her. When he decides to go to New York on a new job assignment, she reads his indifference and claims that it is a lame excuse that he couldn't sit beside her and watch the disease kill her. She yearns in vain to spend a sabbatical with him before she fully succumbs to the disease. Alice starts losing confidence when her own children and husband fail to empathize with her. All she needs from them is something beyond empathy, an encompassing understanding that gives her the feeling of not being excluded in the family:

[T]he key psychological task in dementia care is that of keeping the sufferer's personhood in being. This requires us to see personhood in social rather than individual terms ... in a context of psychological abundance, where interdependence is openly acknowledged... dementia would not turn out to be such a tragedy, and dementia care not so great a burden. Rather, it may become an exemplary model of interpersonal life, an epitome of how to be human. (Kitwood and Bredin 1992:269, 286)

A speech that Alice gives at a Dementia Care Conference vividly portrays her identity crisis and her struggle to overcome it. The great feature of the novel is that it is written from the victim's point of view. We see the world of dementia through the eyes of the victims who are marginalized and penalized for no fault of theirs. It falls in the hands of the care takers to help AD victims live with emotions. But often they become agents of establishing an 'otherness' in the victims.

The self has slowly unraveled and "unbecome" a self, but the caregivers take the role of the other and assume that there is a person behind the largely unwitting presentation of the self of the victims albeit in reality there is less and less, until where once there was a unique individual there is but emptiness. Witnessing, as the "other," the "unbecoming of the self, creates a feeling of emptiness in the caregivers' hearts. Thus, they act as agents for the victim and impute to him or her the last remnants of self. (Fontana and Smith 1989:45)

The members of Alice's family sometimes treat her as if she never existed at all. They give her instructions to help her keep things in her memory as if she was reluctant to do so. Alice feels helpless and her failing vocabulary does not help her explain her inability to remember things.

The feeling of not owning one's self is the most pathetic form of identity crisis. At times, Alice understands many things. But she does not know if she would recognize even very familiar details after a few minutes. Even while presenting her ideas at the dementia care conference, she expresses her identity crisis with the help of highlight makers, so that she does not get lost in between. The billion dollar questions that go unanswered, silenced in the heart of speechlessness are highlighted by Alice's downpour of emotions of deprivation: "What if I don't know where I am or recognize myself in the mirror? When will I no longer be me? Is the part in my brain that's responsible for my unique 'me-ness' vulnerable to this disease. Or is my identity something that transcends neurons, proteins, and defective molecules of DNA? Is my soul and spirit immune to the ravages of Alzheimer's? I believe it is." (282) At this point, Genova doubly emphasizes that the soul and heart of the AD victims are left undamaged and that they possess feelings and a strong desire to express themselves that is accompanied by a strong desire and yearning to be heard. People fail to recognize this fact and they underestimate them:

Being diagnosed with Alzheimer's is like being branded with a Scarlet A. This is now who I am, someone with dementia. This was how I would, for a time; define myself and how others continue to define me. But I am not what I say or what I do or what I remember. I am fundamentally more than that. (282)

While being diagnosed with AD itself is humiliating and branding, it adds more insult to injury to literally be tagged physically with such an identity. Alice hated to wear a most unwanted jewel- a bracelet with the code number- one hundred and eight- and the words "memory impaired" engraved on it, that she is forced to wear in the name of protection. Alice feels that the bracelet is a license that is provided by medical world to brand her mentally ill. But Alice re-ascertains her 'self' and identity by proclaiming that she is not just what the world sees her. She is much more than that and is more successful in leading a meaningful life by "helping others with dementia live better with dementia" (283) by organizing such conferences and helping people with dementia connect with each other for better living. She declares, "I am not someone dying. I am someone living with Alzheimer's." (ibid) She feels confident when she identifies herself with the great mass of people with similar problems at the Dementia Care Conference; "She was Alice Howland, brave and remarkable hero." (286) But when she is alone, she feels scared to step into the bath tub, identifying herself as 'Alice Howland, Alzheimer's victim.' (287)

From Alienation to socialization

When Alice spends her time at Harvard she reminisces about how busy she was before she was diagnosed with AD. When she openly declares her disease, she sees how much she is alienated by her colleagues. They feel sorry for her destiny. But they leave her immediately as if they would also get contaminated. Alice's struggle to banish alienation and to overcome the angst due to alienation is remarkable. She loses friends because of her early onset Alzheimer's and at Harvard she feels "bored, ignored and alienated in her own office. She didn't belong there anymore." (232) She feels the urge to find a space where she belongs - a space where she could find her counterparts with AD. "Surely she wasn't the only one anywhere. She needed to find her new colleagues. She needed to inhabit this new world she found herself in, this world of dementia." (232) She succeeds in finding Mary, Cathy and Dan, who are

AD victims, with whom she spends good time sharing their episodes of memory loss and more other useful information on AD and dementia care.

The socio - cultural construct of Alzheimer's disease

The cultural construct of AD is so demeaning that Alice wished that she had cancer instead of Alzheimer's: "With cancer she'd have something that she could fight. There was surgery, radiation, and chemotherapy" (131). She had chances to recover fully. "Her family and the community at Harvard would rally behind her battle and consider it noble"(ibid). While the bald head of the cancer patient symbolizes courage, hope and may elicit empathy from Alice's failing vocabulary and diminishing memories are symbols of mental instability, "Even the well intentioned and educated tended to keep a fearful distance from the mentally ill." (132) Genova portrays how a disease and the way the public approached the patients is a cultural, social and political construct of those in power – those who have not experienced marginalization. AD was not considered a disease at all. Old age was considered a second childhood, when children of the family took good care of the elders with love and empathy. But today "a 'loss of self' is implicit in the current Alzheimer's construct, and it has been argued that, consequently, the subjective experience of being and becoming old has become increasingly distressing." (Herskovits, 146-164)

Recreation - a new world

In his volume collecting narratives of dementia sufferers, Post dwells at length on the autobiographical story of Jan ("only lightly edited"), who finds meaning in snowflakes: "It had snowed and I had truly forgotten what a beautiful sight a soft, gentle snowfall could be. ... God had granted me the ability to see a snowfall, through the same innocent eyes of the child I once was. . . My husband says I am more content now than ever before!" Alice also has similar experiences of childlike innocence. Genova brings out the second childhood in Alice in many instances, especially, when she takes enough care in eating her ice cream. Nothing else matter to her. She he wants only cold ice creams to taste and the warmth of holding John's hands. At another instant, when Carole, Alice's care-taker, finishes her day of care-taking, she reports the day to Anna. Anna enquires if her mom was wandering around. Carole replies that Alice is her "...trusty shadow now. My partner in crime. Right Alice? (324) Alice smiled and nodded back she had no idea what she was agreeing to. But it was probably fine with her if the woman thought so" (ibid) Alice is no more than a little kid in this instant, just loving the company of her care-taker.

Translating Emotions

With the decline of her comprehensive skills, Alice's "sensitivity to what wasn't said, to body language and unspoken feelings, had heightened."(191). When the whole family cheers on the event of Anna's pregnancy, none other than Alice notice the "thick layer of nervousness covering a thicker layer of terror" (191) in Charlie's face. She wonders if Charlie was worried about having two kids in college and treating his wife suffering from dementia. Alice could read everything through eyes, gestures and body language . She reads Tom with the concern of a mother, "Tom's smiles was genuine, but Alice saw subtle uneasiness about him..'(192) Alice and her grandchildren are taken care of by Carole. Even as she succumbs to AD, her word power diminished, her intelligence declined, her body wasted due to disease and worries, she still can understand, respond and exchange love in an infant's world: "The baby's big round eyes met Alice's and he smiled in recognition" (324) Alice proves her intelligence, the intelligence that goes beyond words – words written, words spoken. Her recognition of words unsaid – words that are sweeter because they are unsaid – words that are more powerful because they are unheard – but felt. Alice's younger daughter Lydia, is an actress. She enacts a monologue, asking her mom to tell her what the scene is about. Alice nodded and she, "...watched and listened and focused beyond the words the actress spoke. She saw her eyes become desperate, searching, pleading for truth.... Her eyebrows and shoulders and hands softened and opened, asking for acceptance and offering forgiveness. Her voice and body created an energy in Alice and moved her to tears. (326) When Lydia asks her to explain the scene, she says, " I feel love. it's about love" (327) and Lydia hugged and kissed her mom and said "You got it exactly right"(ibid)

Genova takes the readers to the most blissful world of Alice. The world Alice wanted to inhabit, with her family, her children and her grandchildren. The loss of memory and language in Alice does not mean the death of life-spirit in her. Genova explains this through her narrative technique. With the slow degeneration of Alice's memory and

vocabulary, the narration takes a dramatic form. She dramatizes events as they appear to Alice. Anna and Lydia are referred to as "the mother" and "the actress". Alice observes and understands what happens around in her and enjoys her new world of dementia.

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