

# Still Alice Book Chat

## Quality Palliative Care in Long Term Care Alliance (QPC-LTC)



Social Sciences and Humanities  
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sciences humaines du Canada







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Larocque N, Schotsman C, Kaasalainen S, Crawshaw D, McAiney C. & Brazil, E. (2013). The use of a book chat to influence attitudes and perceptions of long term care staff about dementia. Accepted for publication, *Perspectives*.

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**Still Alice, Quality Palliative Care in Long Term Care, Version 1,**  
[www.palliativealliance.ca](http://www.palliativealliance.ca).

*“The book is about a young woman’s descent into dementia. And of course, we see her struggle against this horrifying and inevitable descent. But interestingly, as her cognitive capabilities diminish, we also get to see her grow.” Lisa Genova*

## Introduction

This Toolkit is designed to empower healthcare providers, caregivers and volunteers to hold a small guided group discussion on the obstacles surrounding a diagnosis of dementia. The following information was obtained from a book chat held at Allendale Village in a project entitled: Improving Quality of Life for People Dying in Long-Term Care Homes.

The development of this Toolkit was made possible due to research conducted by Dr. Sharon Kaasalainen, Diane Crawshaw and Natasha Larocque for the Quality Palliative Care in Long Term Care Alliance (QPC-LTC).

## Synopsis: *Still Alice*- by Lisa Genova

“Alice Howland is proud of the life she has worked so hard to build. A Harvard professor, she has a successful husband and three grown children. When Alice begins to grow forgetful at first she just dismisses it, but when she gets lost in her own neighbourhood she realizes that something is terribly wrong. Alice finds herself in the rapid downward spiral of Alzheimer’s disease. She is only 50 years old.

While Alice once placed her worth and identity in her celebrated and respected academic life, now she must re-evaluate her relationship with her husband, her expectations of her children and her ideas about herself and her place in the world.

Losing her yesterdays, her short-term memory hanging on by a couple of frayed threads, she is living in the moment, living for each day. But she is still Alice.

*Still Alice* is as compelling as *A Beautiful Mind* and as powerful as *Ordinary People*. You will gain an understanding of those affected by early-onset Alzheimer’s and remain moved and inspired long after you have put it down.”<sup>7</sup>

## Goals

The major goal of the book chat was to bring families and staff together to talk about dementia through the lens of a book.

- Readers build empathy and understanding for people with dementia by following the protagonist's experience
- The book chat provides an opportunity to discuss care for people in the later stages of dementia
- The book chat discussion allows one to explore the family member's experience surrounding a loved one's diagnosis of dementia

Those who participated in the book chat stated that the novel influenced their attitudes and perceptions towards dementia. Participants also commented on how the novel impacted their practice when providing care to dementia residents. Participant comments included:

Better understanding that anyone could develop dementia and the importance of seeing the person behind the disease

*"It makes you think that this could happen to a loved one. And having these different information sessions and reading this book gives you the tools to take care of people with dementia. Treating people with dementia as a whole person [...] it also helps you understand the decisions that the family members make."*

Developing new personal connections with residents who suffer from dementia

*"[The book] provides spiritual care first hand and has helped me connect with dementia sufferers through story, images and familiar aspirations."*

Greater understanding of family situations

*"I have learned to be less judgmental of the family situations."*

Greater sense of empathy and understanding

*"I try hard to get to know the person, not the dementia. It has made me look at the family and life before."*

Impacts on care practices

*"I learned slower is faster with people with dementia."*

*"We as caregivers need to go in with patience and understanding."*

## Planning a Still Alice Book Chat

The success of the book chat was largely due to the communication and planning that occurred weeks before the book chat took place. The Life Enrichment department hosted the event which allowed for greater internal promotion.

Another key player in the planning of the book chat was a representative from the local Alzheimer's Society. Her experience in preparing similar events and first-hand knowledge of the obstacles faced by persons with Alzheimer's disease proved to be invaluable and allowed for a much richer discussion.

**Step 1: Contact your local Alzheimer's Society to see if someone is available to facilitate a *Still Alice* book chat.**

**Tip:** To find your local Alzheimer's Society please visit <http://www.alzheimer.ca/en/on/postal-code>

Community Partners can be very helpful in supporting educational events. The Alzheimer's Society has expertise in dementia and can support learners with additional materials and inform participants of other educational opportunities.

**Step 2: Find *Still Alice* books or a way for potential participants to access the book.**

It is important to have access or to provide residents, families and staff with a list of ways they can access books. Your Long Term Care (LTC) home may want to purchase books and have them available through the recreation department. You may also want to: contact your local library to see if they have copies or see if a local bookstore will donate some copies to your home. Amazon as well as other online bookstores have used copies available for a few dollars per book.

### **Step 3: Plan a Timeline for the event.**

Timelines are important to make this event successful. Consider the following components and timeframes when creating your own timeline.

**Tip:** Allow participants 6 weeks to read the book prior to book chat.

1. Recreation staff to find novels and make handouts for potential participants on where to find/access novels (2 weeks)
2. Contact your local Alzheimer's Society to determine if they are able to be involved with the book chat and when they are available (3 weeks)
3. Create a timeline that takes into consideration the other activities and training sessions taking place in the LTC home and also the availability of the Alzheimer's Society Staff (1 week)
4. Advertise the training internally, place flyers in the resident rooms, and send an invitation to the families asking them to register (3 weeks)
5. Provide participants with information on how to access the book and give participants enough time to read the book (7 weeks)
6. Hold the book chat (1 or 2 dates and times)
7. Continue the discussion (ongoing after the chat)

### **Step 4: Create Internal advertisements for the event.**

**Ensure to include: date, time, location, who is invited and facilitator.**

**Tip:** To recruit participants hold event over lunch hour to replace traditional "lunch and learns." Administrative buy-in is essential for good attendance.

### **Step 5: Advertise the event within the LTC home**

Sending the families the advertisement in the mail is a good way of letting them know about the event. LTC home newsletters, in-service boards, and palliative care boards can also be important advertising techniques. See appendix A for a sample advertisement.

**Tip:** Put plenty of flyers in the rooms of residents and near the nursing stations

**Step 6: Keep the Discussion Going.**  
**Due to the work schedule in LTC,**  
**all staff may not be able to attend**  
**the book chat.**

Consider activities that will encourage staff to continue to talk about the book. Have staff “leaders” talk about the event in various interprofessional team meetings (example: staff meetings, palliative care team meetings)

**Tip:** Finding ways to facilitate this informal discussion will be key to continuing the education after the book chat is complete.





## Book Chat Questions

1. When Alice becomes disoriented in Harvard Square, a place she's visited daily for twenty-five years, why doesn't she tell John? Is she too afraid to face a possible illness, worried about his possible reaction, or some other reason?
2. After first learning she has Alzheimer's disease, "the sound of her name penetrated her every cell and seemed to scatter her molecules beyond the boundaries of her own skin. She watched herself from the far corner of the room" (pg. 70). What do you think of Alice's reaction to the diagnosis? Why does she disassociate herself to the extent that she feels she's having an out-of-body experience?
3. Do you find irony in the fact that Alice, a Harvard professor and researcher, suffers from a disease that causes her brain to atrophy? Why do you think the author, Lisa Genova, chose this profession? How does her past academic success affect Alice's ability, and her family's, to cope with Alzheimer's?
4. "He refused to watch her take her medication. He could be mid-sentence, mid-conversation, but if she got out her plastic, days-of-the-week pill container, he left the room" (pg. 89). Is John's reaction understandable? What might be the significance of him frequently fiddling with his wedding ring when Alice's health is discussed?
5. When Alice's three children, Anna, Tom and Lydia, find out they can be tested for the genetic mutation that causes Alzheimer's, only Lydia decides she doesn't want to know. Why does she decline? Would you want to know if you had the gene?
6. Why is her mother's butterfly necklace so important to Alice? Is it only because she misses her mother? Does Alice feel a connection to butterflies beyond the necklace?
7. Alice decides she wants to spend her remaining time with her family and her books. Considering her devotion and passion for her work, why doesn't her research make the list of priorities? Does Alice most identify herself as a mother, wife, or scholar?

8. Were you surprised at Alice's plan to overdose on sleeping pills once her disease progressed to an advanced stage? Is this decision in character? Why does she make this difficult choice? If they found out, would her family approve?
9. As the symptoms worsen, Alice begins to feel like she's living in one of Lydia's plays: "(Interior of Doctor's Office. The neurologist left the room. The husband spun his ring. The woman hoped for a cure.)" (pg. 141). Is this thought process a sign of the disease, or does pretending it's not happening to her make it easier for Alice to deal with reality?
10. Do Alice's relationships with her children differ? Why does she read Lydia's diary? And does Lydia decide to attend college only to honor her mother?
11. Alice's mother and sister died when she was only a freshman in college, and yet Alice has to keep reminding herself they're not about to walk through the door. As the symptoms worsen, why does Alice think more about her mother and sister? Is it because her older memories are more accessible, is she thinking of happier times, or is she worried about her own mortality?
12. Alice and the members of her support group, Mary, Cathy, and Dan, all discuss how their reputations suffered prior to their diagnoses because people thought they were being difficult or possibly had substance abuse problems. Is preserving their legacies one of the biggest obstacles to people suffering from Alzheimer's disease? What examples are there of people still respecting Alice's wishes, and at what times is she ignored?
13. "One last sabbatical year together. She wouldn't trade that in for anything. Apparently, he would" (pg. 223). Why does John decide to keep working? Is it fair for him to seek the job in New York considering Alice probably won't know her whereabouts by the time they move? Is he correct when he tells the children she would not want him to sacrifice his work?

14. Why does Lisa Genova choose to end the novel with John reading that Amylix, the medicine that Alice was taking, failed to stabilize Alzheimer's patients? Why does this news cause John to cry?
  
15. Alice's doctor tells her, "You may not be the most reliable source of what's been going on" (pg. 54). Yet, Lisa Genova chose to tell the story from Alice's point of view. As Alice's disease worsens, her perceptions indeed get less reliable. Why would the author choose to stay in Alice's perspective? What do we gain, and what do we lose?



## Appendix A: Sample Advertisement



# *Still Alice* *Book Chat*



Reading *Still Alice* builds empathy and understanding for people with dementia.

The Palliative Care Project invites everyone to partake in a **drop in** book chat on **Tuesday June 21<sup>st</sup> from 1:30 to 4:00 in the main Courtyard**

This will be an opportunity to discuss care in the later stages for residents with dementia. All are welcome, it is not necessary to have read the book to participate in this event. You can stay for a few minutes or longer. Light snacks will be served.



## References

1. Genova L. Still Alice. New York: Pocket Books; 2009.

## Key Partners



## Funders



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