



A New Journey: Early-Onset Dementia -By Cassandra Van Dyck

"The mother in her believed that the love she had for her daughter was safe from the mayhem of her mind, because it lived in her heart." - Lisa Genova

Still Alice tells the story of a fifty year-old cognitive psychology professor, wife, and mother who is diagnosed with early-onset genetic Alzheimer's disease. Alice must come to terms with her diagnosis and changing relationships with her family while experiencing the effects of Alzheimer's. I watched the film just over a month ago and still feel haunted by how quickly the disease affected Alice's quality of life, despite her healthy lifestyle, age, and education. It can feel frightening to imagine yourself or someone close to you going through what Alice's character did. After thinking about the film for a while, I realized that although *Still Alice* could be categorized as a sad movie, it could also be filed under some other groupings. Alice's diagnosis did not mean her life was ending, but that it was changing. The journey through her illness was not just sad, but romantic, inspirational, and loving.

Diagnosis

Early-onset dementia disease, commonly known as early-onset Alzheimer's, can occur in people in their 30s, 40s, or 50s. "Dementia" refers to a group of symptoms that affect mental tasks and Alzheimer's is the most common type diagnosed. It can be categorized as either "common" or "genetic." Most people diagnosed will have common early-onset, which progresses similarly to the way it would in someone older. Genetic early-onset is extremely rare. The symptoms of both types are the same as Alzheimer's diagnosed later in life: difficulty solving problems, forgetting important dates or things, losing track of where you are and how you got there, etc. If Alzheimer's disease is suspected, doctors will run a series of tests before making a diagnosis. Early-onset Alzheimer's can be particularly challenging for people to accept and adapt to. Generally, there is some expectation that at a certain age, one will not function at the same level they were once able to. People do not usually expect this to happen in their 30s, 40s, or 50s, especially when the changes affect their memory, their ability to care for themselves, and the capacity to socialize. It is natural for those affected and for caregivers to feel fear, grief, and frustration.

Communication

One of the ways caregivers can help themselves to manage fear and frustration is to increase their knowledge base so they can better communicate with their loved ones. When someone is diagnosed with early-onset Alzheimer's disease, it can become increasingly difficult to have conversations similar to those you used to have or to explain things if they are confused, such as why you need to go to certain appointments or how members of your family are connected. It may be hard to know when to correct your care partner and when to accept their view of an event or situation. Fortunately, there are resources that can help caregivers navigate this new journey. Claudia J. Strauss' book, *Talking to Alzheimer's*, may be very helpful. It is meant to be used as a reference guide for those struggling with particular issues, such as how to handle repetition, saying "no" without causing mishap, and how to start a conversation. Strauss gives examples and suggestions for managing many situations, but the undercurrent to her book seems to be the willingness to listen and to learn how to redirect a conversation if necessary. Taking the time to really hear what your loved one is saying can be more helpful than trying to stop them from saying what they need

to. When there is a pause, you may be able to pick up on part of what they've said and take the conversation another way.

Self-Care

Along with pages of communication tips, Strauss emphasizes the importance of caregivers' self-care. It can be very hard to watch your loved one's abilities change and even harder to care for them if you are not taking care of yourself. Grief is a very common part of a caregiver's journey, and it can be helpful for caregivers to reach out to family members and friends, support services and network groups. Remember to ask for help with tasks, and to take the time to do one thing every day just for you—even if it is as simple as enjoying a cup of tea or taking a bath. If you are caring for your loved one at home, it can require a great reserve of patience, making these breaks all the more useful. Consider using respite services if you feel that you need a longer break, or asking a family member or friend to spend some time with your loved one so you can go for a walk or coffee by yourself. If you are caring for someone in facility care, it can be helpful to check in with yourself to see how you are feeling about visiting. While Strauss does recommend letting too much time go between visits with someone with dementia, she does encourage caregivers not to get too caught up in feeling that they have to visit for a certain amount of time or on regular days. It's important to listen to yourself and what you need, as well. If you are not feeling up to visiting, or if the visit feels too much to handle, the best thing you may be able to do for yourself that day is to stay home or leave earlier. Coping with early-onset Alzheimer's disease can be incredibly trying, but it may help to think of it as the start to a new journey, instead of the end of an old one.

“If you put the disease in the background and the person in the foreground, always remembering who he is, then you will be like the sun shining light toward him and he will shine light back on you.”
- Claudia J. Strauss

For more resources, see our Wellness Corner on page 4. For more self-care tips, read our Self-Care for the Holidays article on page 5.

