INFLUENCE | FILM FORUM

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The Genius of Marian Discussion Guide

Directors: Banker White, Anna Fitch Year: 2013 Time: 86 min

You might know this director from: Refugee All Stars, Sierra Leone's (2005)

FILM SUMMARY

THE GENIUS OF MARIAN is a visually rich, emotionally complex story about one family's struggle to accept the changes that Alzheimer's disease brings. When Pam White is diagnosed at age 61 with early onset Alzheimer's, life begins to change, slowly but irrevocably, for Pam and everyone around her. Pam's husband grapples with his changing role from primary partner to primary caregiver. Pam's adult children find ways to show their love and support while mourning the slow loss of their mother. Meanwhile, Pam begins a journey from fear to acceptance of the disease that makes her constantly more dependent on others for the basic functions of daily life.

As she loses the ability to write, Pam's eldest son, Banker, records their conversations, allowing her to share memories of childhood and of her own mother, renowned painter Marian Williams Steele. Marian, who died of Alzheimer's in 2001, was a central figure in Pam's life — and Marian's spirit is strongly felt in the film.

Pam must confront the guilt of putting her mother in a nursing home and the fear that she, too, will end up in an institution. Gradually, she comes to terms with her disease and finds solace in the sense of humor and joy Marian retained throughout her own battle with dementia. THE GENIUS OF MARIAN serves as a meditation on the impact of Alzheimer's disease, the power of art, and the meaning of family.

* This Discussion Guide was made in collaboration with the filmmakers of THE GENIUS OF MARIAN.

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FILM THEMES

The film is primarily about Alzheimer's – a deadly, progressive disease that slowly impairs a person but impacts everyone around them. Thus, the film is really about loss, about self-hood, and most of all, family.

FAMILY CAREGIVING

As Alzheimer's disease progresses, the responsibility of family members increases dramatically. It's important to recognize the well-being of those who carry the weight of this responsibility as their lives begin to become impacted on a daily basis. Those with Alzheimer's undergo constant changes, which might bring additional responsibilities, loss of personal time or independence, and emotional shifts within the relationship. Family members can quickly become exhausted, all the while grieving the loss of the person they knew before the diagnosis, coping with financial strain, social stigmas, and

CREATIVE ENGAGEMENT

Physical and mental exercises should be encouraged to stimulate the brain. Physical activity can counteract declining hippocampal function, reduce pathological features, and boost the immune system. For mental exercise, experts say it's best to avoid repetitive tasks. Instead, choose mental exercises that are challenging but not too stressful. Art therapy can also be powerful, as "the very process of being a creator empowers by allowing for a flow of energy and life," said Dr. Patricia Baines.

STIGMA

Stigma directly impacts the person with Alzheimer's and those who love them. In today's society, Alzheimer's is whispered much in the same way cancer was fifty years ago. As a result, people who have Alzheimer's and those who love them are less likely to talk directly about how the disease is affecting them. Stigmas make it difficult, if not impossible, for family members to deal with day-to-day caregiving roles and their emotions. Discussing the stigmas openly and frankly, however, can help facilitate conversations about Alzheimer's disease, its progression, effects, and next steps in caregiving.

INDEPENDENCE

We are a society of independent people. Especially in the western world, we are taught to think for ourselves, make our own choices and march to the beat of our own drums. Alzheimer's disease, over time, strips away one's independence. With the loss of independence comes the fear of losing oneself to the disease. According to the Alzheimer's Society, people are happier when they are treated as competent, independent individuals who can stay in their own homes for as long as possible, even if that means adapting their homes in order to diminish risks. "I live for my family and my children, and one little glitch is that I have developed Alzheimer's. Initially, I was quite distressed and upset about it, but it doesn't really matter. It doesn't change anything."

Pam White

"There is so much tension in loving someone who is in the process of changing, who will inevitably die because of this disease."

Banker White

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FURTHER DISCUSSIONS:

- 1. What is your experience with family caregiving? Have you ever been in a position of having to care for family members or friends? Have you ever been on the receiving end?
- 2. What kind of support do you think caregivers need, and how can they access that sort of support?
- 3. What did you think of Pam's video diary entry at the end of the film, when says that her Alzheimer's doesn't really matter, that she doesn't feel sad or regret, but only gratefulness for her wonderful family? How different was this Pam from the Pam you met at the beginning of the film?
- 4. What are some ways for a person with Alzheimer's to stay mobile and engage in independent activities, to retain their sense of self?
- 5. Experts agree that the arts play a huge role in the life of people with Alzheimer's. Why so, do you think? What does art and creativity give to people? How powerful is it? And should we find ways of expressing ourselves all throughout our lives, dementia or not?
- 6. Is the stigma related to dementia and Alzheimer's similar or different from stigmas toward other mental illnesses that also affect one's ability to think and function, such as depression or anxiety?
- 7. How do stigmas and secrecy affect people? Have you ever hidden a personal experience because you feared the social consequences? How would your experience have been different if you had felt comfortable enough to discuss it openly and frankly?
- 8. In watching Pam's daily activities, what surprised you most about her diminishing abilities? What changes did you notice as she lost her ability to be independent?
- 9. The issue of independence (especially driving or dressing) is a difficult one that many people with Alzheimer's must eventually face. How difficult do you think it would be to give up driving? How difficult would it be to let someone dress you every day? How should families address these issues?
- 10. Life, memory and money these things fade and disappear. So what endures of a person's life? What do you want to leave behind?

NOTES:

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FILM FACTS:

- 1 in 3 senior citizens dies with Alzheimer's or another form of dementia.
- In 2013, 15.5 million caregivers provided an estimated 17.7 billion hours of unpaid care valued at more than \$220 billion USD.
- Alzheimer's disease is the 6th leading cause of death in the United States.
- For a woman in her 60s, the estimated lifetime risk for developing Alzheimer's is 1 in 6. For breast cancer it is 1 in 11.
- There are 2.5 times more women than men providing intensive "on-duty" care 24 hours a day for someone with Alzheimer's.
- According to the Alzheimer's Association, Alzheimer's disease is the most expensive condition in the U.S. In 2014, the direct costs of caring for those with Alzheimer's will total an estimated \$214 billion in the U.S., including \$150 billion in costs to Medicare and Medicaid.
- Alzheimer's caregivers have an increased likelihood of physical strain, mental and emotional stress, depression, financial problems, and familial/interpersonal issues.

- An estimated 800,000 Americans with Alzheimer's are living alone.
- In 2012, the average annual cost of health care and long-term care services for someone with Alzheimer's was \$43,847 USD.
- Out of approximately 5.4 million Americans with Alzheimer's, more than half may not know they have it.
- Filmmaker Banker White is the director and producer of the award-winning film, Sierra Leone's Refugee All Stars, which tells the story of a group of six Sierra Leonean musicians.
- Banker White said, "I didn't originally set out to make a documentary film about my mother's disease. The project began as a series of informal recorded conversations with my mom in the months after her Alzheimer's diagnosis in 2009. She had begun writing a memoir called "The Genius of Marian" about her own mother (my grandmother), Marian Williams Steele. Soon after my mom started writing the book, she began to struggle with typing and other mental tasks. To help her continue the project, I began filming our conversations."

WAYS TO INFLUENCE

- 1. Share this film so that the millions of people whose lives are affected by Alzheimer's might find solidarity and strength from Pam's journey. Also, consider hosting a screening. Visit the film website to learn more.
- 2. Check out The Genius of Caring, the filmmaker's outreach campaign to support caregivers.
- 3. Go to <u>US Against Alzheimers</u> and join those who are committed to stopping Alzheimers by 2020.
- 4. Participate in the Walk to End Alzheimer's and The Longest Day.
- 5. Learn all you can about Alzheimer's, and do whatever you can to support those who are dealing with. It can be a lonely disease, but it doesn't have to be.

We believe a good documentary is just the beginning...

In a world of sound-bites, documentaries provide an opportunity to think, understand, share, and connect with the world.

They are controversial, divisive, fascinating, unexpected, and surprising. They can be thrillers, dramas, comedies, romance, tear-jerkers, and horror films.

Documentaries provide the perfect topic for meaningful conversations. If you want to talk about the things that matter with people that matter then pick a film, invite your friends, and watch & discuss together. It's as easy as that.

Influence Film Club – We are the conversation after the film.