



### **ABOUT THE FILM**

*The Genius of Marian* is an award-winning PBS film that explores the heartbreak of Alzheimer's disease, the power of art and the meaning of family. The film follows Pam White in the early stages of Alzheimer's disease as her son, the filmmaker, documents her struggle to hang on to a sense of self. By investigating this disease in a warm, poetic and deeply personal way, *The Genius of Marian* is an ideal tool for education and advocacy.

Over 15 million caregivers provide unpaid support for the 5.4 million people in the United States who are living with Alzheimer's disease. *The Genius of Marian* has the power to shift the way we understand caregiving and Alzheimer's, setting the stage for important conversations about how to cope with and care for this growing population.

### **DIRECTOR'S STATEMENT**

I approached this film both as a loving son and as a patient observer. Pam White is my mother. She is a loving parent of three children, a devoted friend, a steadfast partner to my dad Ed, and a gifted clinical social worker. But, as she puts it, "There's just one little glitch." In 2009, shortly after her 61st birthday, she was diagnosed with early-onset Alzheimer's disease.

Creating understanding was her life's work. Throughout her career, my mom has worked to help people to open up and talk about difficult issues. She is a great listener and because of her inviting and warm energy she has always been easy to talk to. Today, three years into her disease process, she understands the world more than ever through her connection to others and her capacity for deep and mutual understanding.

The last few years have been a roller coaster of emotions, filled with frustration, sadness, joy and celebration. I didn't originally set out to make a documentary film about my mother's disease. The project began as a very personal project: a series of informal recorded conversations with my mom in the months after her Alzheimer's diagnosis in 2009. Just before her diagnosis, she had started writing a memoir about her mother, the renowned artist Marian Williams Steele. When she began to have trouble writing, I started filming with her to allow her project to continue and the rest of my family soon also welcomed the camera into their lives.

For the next three years, I recorded both the big events and the small details of my family's changing reality. I filmed my parents recounting stories of how they met and fell in love. I captured my mother's delight at the birth of her grandchildren. But I also documented the slow erosion of my mother's ability to dress and feed herself, her waning independence, and her fierce resistance to accepting help from professional caregivers.

I grew up feeling like my mom could do it all—and often, she did. She worked full-time while raising my siblings and me, maintained deep friendships and dedicated herself to helping others, both in her personal life and in her career as a therapist.

When it became clear that this project would have resonance for the millions of others individuals and families affected by Alzheimer's, we committed to sharing our story through a documentary film. And by bringing *The Genius of Marian* to community centers, conference halls, public theaters and private homes around the country, we hope to carry on my mom's work.

In *The Genius of Marian*, our family's story is depicted with intimacy and honesty, offering audiences a chance to connect to and identify with us as we navigate the changes Alzheimer's has brought to our lives. Although the film is candid in depicting the challenges of family caregiving, its message is ultimately uplifting.

*The Genius of Marian* reveals what we, as a family, discovered through this process: that the only way to start making informed decisions about our own health and the health of our loved ones is to talk openly about aging and loss with our families, our friends and our larger communities. I hope this film will make a significant contribution to sparking those all-important conversations.

Banker White

*The Genius of Marian*

## **SCREENING OBJECTIVES**

*The Genius of Marian* is an intimate portrait of a family dealing with the realities of dementia and Alzheimer's disease. It is an emotional story that touches on many themes that could be explored during discussion before and after screening the film. Discussion can be for the purpose of personal reflection, professional development, or furthering an ongoing dialogue about how Alzheimer's disease and family caregiving are affecting the current political and health care climate in the United States.

## **BEFORE THE FILM**

When people arrive at the screening, hand out the one-page survey and story sharing exercise that is included in your screening kit. Introduce the film and let the audience know there will be a discussion after the screening.

## **AFTER THE FILM**

After the film, allow viewers several minutes to quietly process what they have seen, before posing any questions or starting any activities. Plan the discussion based on your audience and the amount of time you have. If you are screening in large group setting, it may help discussion of such personal and emotional content if you allow viewers to break into small groups for part of the discussion.

Consider inviting one or more medical professionals, caregivers, or people living with Alzheimer's to answer questions and participate in the post-screening discussion. A large audience might benefit from a panel after the screening that could answer audience questions and focus reaction and conversation around the film.

To begin a post-screening discussion, you may want to use the following questions and ask for a show of hands to give people a sense of who else is in the room.

*How many people in the room have been somehow touched by Alzheimer's disease?*

*How many people have a personal experience with caregiving?*

If it is appropriate for your group, you may want to invite members of your audience to share their own personal experiences related to Alzheimer's disease and caregiving. Be sure to set expectations about how long people have to talk. It can be helpful to set specific time limits to allow more people to share.

Whether you have a panel, or you are facilitating a group discussion with the audience, you can use the list of questions and themes on the following page to guide your discussion.

Don't forget to leave time at the end of your discussion for people to complete the survey and story sharing exercise (included in your screening kit).

## **THEMES & QUESTIONS**

### **Family Caregiving**

- After watching the White family care for Pam, what comes up for you with respect to family caregiving?
- How can family and friends access support for themselves and for their caregivers?
- What are ways they can ask for help and reduce the stress in their lives?
- How can friends and others who are not primary caregivers best support loved ones with Alzheimer's disease?

### **Creative Engagement**

- What role do creative engagement and the arts play in the lives of people with Alzheimer's disease?

### **Independence**

- In what ways do leisure time or work change as a person living with Alzheimer's loses his or her ability to be independent?
- The issue of independence and driving is a difficult one that many people with Alzheimer's must eventually face. What are your thoughts about giving up driving? How should families address this issue?
- What is the best way for a person with Alzheimer's to stay mobile and engage in independent activities?

### **Stigma**

- Is the stigma related to dementia and Alzheimer's different from stigma toward other mental illnesses that also affect one's ability to think and function day to day, such as depression or anxiety?
- How does stigma affect the family caregiver and caregiving circle?

### **Medical Care**

- How is Pam's experience with medical care the same or different from experiences you have had?
- How/when/should medical providers for the diagnosed person offer support to the family?
- What kind of a team of medical professionals does a person need as they go through the progressive stages of Alzheimer's disease?

### **Preparing for Stages of Disease**

- What are the various stages of Alzheimer's disease?
- How can a family prepare emotionally and practically for these inevitable changes?
- What are the legal and financial issues that a person with Alzheimer's and their family must face?
- What are your thoughts about advanced directives for someone with Alzheimer's disease and their family?

**FURTHER DISCUSSION**

After watching *The Genius of Marian*, audiences may feel inspired to learn more and engage further with the project.

Please share the following resources for connecting with partner organizations and the broader community of patients, families, friends, caregivers and professionals.

**Alzheimer's Association**

Website: [www.alz.org](http://www.alz.org)

24/7 Helpline: (800) 272-3900

**Trial Match** (to participate in clinical trials)

[http://www.alz.org/research/clinical\\_trials/find\\_clinical\\_trials\\_trialmatch.asp](http://www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp)

**Alzheimer's Foundation of America**

[www.alzfdn.org](http://www.alzfdn.org)

**USAgainstAlzheimer's**

[www.usagainstalzhimers.org](http://www.usagainstalzhimers.org)

**Home Instead**

<http://www.homeinstead.com/Pages/home.aspx>

**Arts and Minds**

<http://www.artsandminds.org>

**Mayo Clinic**

<http://www.mayoclinic.com/health/alzheimers-disease/DS00161>

## THE GENIUS OF MARIAN - A FILM BY BANKER WHITE

### ADDITIONAL INFORMATION



**Alzheimer's One-Sheet (courtesy of the Alzheimer's Association)**

**For more information, visit [www.alz.org](http://www.alz.org)**

#### **Alzheimer's and dementia basics**

- **Alzheimer's is the most common form of dementia**, a general term for memory loss and other intellectual abilities serious enough to interfere with daily life. Alzheimer's disease accounts for 50 to 80 percent of dementia cases
- **Alzheimer's is not a normal part of aging**, although the greatest known risk factor is increasing age, and the majority of people with Alzheimer's are 65 and older. But Alzheimer's is not just a disease of old age. Up to 5 percent of people with the disease (more than 200,000 people in the United States alone) have early onset Alzheimer's (also known as younger-onset), which often appears when someone is in their 40s or 50s.
- **Alzheimer's worsens over time.** Alzheimer's is a progressive disease, where dementia symptoms gradually worsen over a number of years. In its early stages, memory loss is mild, but with late-stage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment. Alzheimer's is the sixth leading cause of death in the United States. Those with Alzheimer's live an average of eight years after their symptoms become noticeable to others, but survival can range from four to 20 years, depending on age and other health conditions.
- **Alzheimer's has no current cure, but treatments for symptoms are available and research continues.** Although current Alzheimer's treatments cannot stop Alzheimer's from progressing, they can temporarily slow the worsening of dementia symptoms and improve quality of life for those with Alzheimer's and their caregivers. Today, there is a worldwide effort under way to find better ways to treat the disease, delay its onset, and prevent it from developing.

#### **Symptoms of Alzheimer's**

**The most common early symptom of Alzheimer's is difficulty remembering newly learned information.**

Just like the rest of our bodies, our brains change as we age. Most of us eventually notice some slowed thinking and occasional problems with remembering certain things. However, serious memory loss, confusion and other major changes in the way our minds work may be a sign that brain cells are failing.

The most common early symptom of Alzheimer's is difficulty remembering newly learned information because Alzheimer's changes typically begin in the part of the brain that affects learning. As Alzheimer's advances through the brain it leads to increasingly severe symptoms, including disorientation, mood and behavior changes; deepening confusion about events, time and place; unfounded suspicions about family, friends and professional caregivers; more serious memory loss and behavior changes; and difficulty speaking, swallowing and walking.

### **Alzheimer's and the brain**

#### **Microscopic changes in the brain begin long before the first signs of memory loss.**

The brain has 100 billion nerve cells (neurons). Each nerve cell connects with many others to form communication networks. Groups of nerve cells have special jobs. Some are involved in thinking, learning and remembering. Others help us see, hear and smell.

To do their work, brain cells operate like tiny factories. They receive supplies, generate energy, construct equipment and get rid of waste. Cells also process and store information and communicate with other cells. Keeping everything running requires coordination as well as large amounts of fuel and oxygen.

Scientists believe Alzheimer's disease prevents parts of a cell's factory from running well. They are not sure where the trouble starts. But just like a real factory, backups and breakdowns in one system cause problems in other areas. As damage spreads, cells lose their ability to do their jobs and, eventually die, causing irreversible changes in the brain.

### **Research and progress**

#### **Today, Alzheimer's is at the forefront of biomedical research.**

Researchers are working to uncover as many aspects of Alzheimer's disease and related dementias as possible. Ninety percent of what we know about Alzheimer's has been discovered in the last 15 years. Some of the most remarkable progress has shed light on how Alzheimer's affects the brain. The hope is this better understanding will lead to new treatments. Many potential approaches are currently under investigation worldwide.