

DISCUSSION GUIDE

THE MEMORY LOSS TAPES

THE ALZHEIMER'S PROJECT

A 4-PART DOCUMENTARY SERIES CHANGING THE WAY AMERICA THINKS ABOUT ALZHEIMER'S DISEASE



HBO DOCUMENTARY FILMS

THE MEMORY LOSS TAPES

INTRODUCTION

This film provides an intimate portrait of seven individuals living with the disease. Among the emotionally gripping stories: a mother who fiercely holds onto her simple lifestyle while realizing her memory loss makes it more difficult to do so; a mother who feels she's lost her independence after failing a driver's test; a woman in a nursing home who thinks her reflection in a mirror is her best friend; a onetime computer whiz who chronicles his activities while he still can; a father who can still steal the spotlight while performing with his vocal group, but can no longer remember his family; a daughter forced to build a fence around her own farm to keep her mother from wandering off; and a former host of a kids' TV show who is brought to a hospice by his wife after his body starts to shut down. This Discussion Guide provides key questions along with practical tips and advice on how to cope with this debilitating disease.

DISCUSSION QUESTIONS AND CONVERSATION STARTERS

THE FILM

1. Based on Bessie, Fanny and Joe, what symptoms do you think are associated with the early stages of Alzheimer's?
2. Fanny seems disappointed and angry about failing her driver's test. Does her level of acceptance of the disease appear to differ from Bessie's and Joe's?
3. Do Bessie, Fanny, and Joe share a concern for loss of independence at this time?
4. Think about the behaviors of the individuals living with Alzheimer's portrayed in the film. What similarities and differences did you observe?
5. Although clearly suffering from the disease, Woody and Cliff appear to have happy dispositions. Would their apparent contentment make things easier or more difficult for their caregivers? How?
6. What social stigmas might those with Alzheimer's, their friends or families face because of the disease?
7. With Cliff's wife, Ann, in mind, what do you think are some of the significant decisions that must be



made by a spouse or caregiver for someone in the later stages of the disease?

8. Yolanda hallucinates about the lady in the mirror and snakes on her chair. Cliff believes he's late for his television show. Their caregivers "play along." Why might this approach be beneficial?
9. Josephine's daughter has fenced in the perimeter of their home. What was your reaction to the fence? Did you view it as an act of love? Why or why not?
10. What responsibilities do caregivers have at various stages of the disease?
11. What are some of the things that caregivers in the film say keep them going? What are some examples of how people with the disease continue to connect to their loved ones?
12. Did you have a reaction to the apparent distress of other residents in Woody's and Yolanda's care centers?
13. How might things like pets or dolls benefit those living with Alzheimer's?

GENERAL

14. How would you describe the difference between getting old and getting Alzheimer's?
15. What distinguishes Alzheimer's from other fatal diseases?
16. What would it feel like to be aware that you have a disease for which there is no known cure? Would you choose to advocate for improved understanding of the disease while or take any other actions you were still able?

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17. What circumstances would make you consider participating in a research study or trial?
18. What warning signs might indicate that someone is suffering from Alzheimer's?
19. Why would early detection of Alzheimer's be beneficial? Why might someone resist testing or diagnosis?

KEY THEMES AND ISSUES

Independence

20. What are the ways in which Alzheimer's erodes independence for both the person with the disease as well as the person/people taking care of him/her?
21. How might a person living with the disease preserve their independence for as long as possible?

Communication

22. How would you interact with someone who is aware that they're experiencing memory loss?
23. How do family and friends interact and communicate differently with someone in the later stages of Alzheimer's?
24. Joe blogged urgently in order to express himself with words before he was unable to do so. How did those in later stages continue to express themselves without words?

Changes in Intimacy, Sexual Behavior

25. Woody appears to have formed a close relationship with Cathy, a fellow patient. What do you think this connection means to Woody? Cathy? Woody's wife? Woody's daughter?
26. How does the expression of sexuality and intimacy appear to change through various stages of the disease?

Caregiving

27. Based on what you've seen in the film, what are some of the emotional, social, and financial costs associated with caregiving?
28. On a walk with her daughter, Josephine puts a stone in her mouth. Later, the daughter berates herself for handing Josephine the stone in the first place. What did you think of this self-criticism?

29. What are some of the ways in which caregivers might care for themselves?
30. What factors would you consider when deciding whether or not to move a loved one into a care facility?

End of Life Choices

31. In a discussion with his therapist, Joe alludes to suicide "when the time comes." How did this make you feel?
32. Near the end of his life, Cliff's wife, Ann, honors his wishes not to be put on life support. If your loved one's wishes were not clear, how would you approach this decision?
33. What are some ways that Alzheimer's patients can plan ahead for the progression of the disease, including end of life choices? How would patients and their families benefit from a plan?

REACTIONS

- Why did you choose to watch this film?
- What made you want to participate in the discussion?
- What were some of your feelings while watching the film?
- What moments in the film affected you the most? Why?
- Whose story did you find the most compelling? Why?
- Did you identify with any of the subjects or their family members in any way?
- What questions, fear or concerns did the film bring to mind?
- What did you learn about Alzheimer's disease while watching this film?
- Are you interested in learning more about any aspect of the disease?
- Do you know where to go for information and or assistance?
- Do you know where to find out about participating in AD research?
- Did you know that people without Alzheimer's can also participate in research about AD?

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MEMORY LOSS TIPS

Here are some tips that can help those affected by Alzheimer's disease deal with some of the issues raised in the films. These are adapted from materials that are published by the Alzheimer's Association and the National Institute on Aging, and much, much more information is available from these organizations. See the Resources section for more details.

Alzheimer's Diagnosis: Who to Tell, How Much and When?

There's really no right answer for this issue. We've come a long way in helping people understand that Alzheimer's is a brain disease, but many people find it mysterious and frightening. Be honest with family and friends about the person's diagnosis, and share educational materials if you think that may help. Talk openly about how the disease could change life as you know it. Be aware that some people may drift away because they are uncomfortable with those changes or with the idea of providing care. Alzheimer's disease also affects children and teens. Just as with any family member, be honest about the person's diagnosis with the young people in your life. Encourage them to ask questions.



Legal and Financial Planning

A diagnosis of Alzheimer's disease is a devastating time in the life of a family. There is so much that everyone needs to process and it seems to happen all at once. In addition to dealing with emotions and medical information, families also need to address issues of legal and financial planning. Shortly after diagnosis, families need to begin long-term planning if they haven't done so already. This will enable the person with Alzheimer's disease to participate in the discussion and make his or her wishes known. This planning will include things like advance directives, wills, estate planning, and various powers of attorney. See the Resources section for more details about these issues.



Safety

Keeping the person safe is of the utmost importance. Some people with AD may wander away from their home or their caregiver. Knowing how to limit wandering can protect a person from getting lost. Make sure that the person carries some kind of identification or wears a medical bracelet.

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See more about the Medic Alert® + Alzheimer's Association Safe Return® Program at the website (www.alz.org). Keep a recent photograph or videotape of the person with AD to assist police if the person becomes lost. Keep doors locked. Consider a keyed deadbolt or an additional lock up high or down low on the door. If the person can open a lock because it is familiar, a new latch or lock may help.

Driving and Independence

Deciding it's time for someone to stop driving is difficult, but safety is the priority. Losing the ability to drive is a blow to independence, and the person with AD may feel angry, depressed or may even forget they can't drive anymore. You can ask a doctor for help, and the doctor also can contact the Department of Motor Vehicles to request that the person be re-evaluated. If necessary, take the car keys. If just having keys is important, substitute a different set of keys.

Communication

Communicating with a person who has AD can be a challenge. Both understanding and being understood may be difficult. Here are a few strategies that may help, but remember you may need to adjust as the disease progresses. Choose simple words and short sentences and use a gentle, calm tone of voice. Minimize distractions and noise – such as the television or radio – to help the person focus on what you are saying. Call the person by name, making sure you have his or her attention before speaking. Try to avoid offering options when they're really aren't any. Allow enough time for a response

Sexuality and Intimacy

Alzheimer's disease changes the functioning of a person's brain. When that happens, the person's sexual behavior can change. Some people may forget appropriate public behavior. Some may use vulgar words or act in a sexually aggressive way toward a spouse or others. Still others may lose interest in sex altogether. It's important to remember that changes in sexual behavior may be related to symptoms of the disease.

Sleep Issues/Sundowning

Many people with AD become restless, agitated, and irritable around dinnertime. This is often called "sundowning" syndrome. A number of strategies may help. Encourage exercise during the day and

limit daytime napping. Try to keep bedtime at a similar time each evening. Set a quiet, peaceful tone in the evening to encourage sleeping, and use night-lights if the darkness is frightening or disorienting. If these ideas don't help, you can consult the doctor for additional suggestions

Problem Behavior: Hallucinations/ Delusions

Some behavior problems are common over the course of the disease, but the occurrence can be highly variable. Two that can be disturbing and difficult to deal with are hallucinations and delusions. As the disease progresses, some people with AD may experience hallucinations and/or delusions. Hallucinations are when the person sees, hears, smells, tastes, or feels something that is not there. Delusions are false beliefs from which the person cannot be dissuaded. These hallucinations and delusions can be signs of physical illness that can be treated. Try to observe if there are any patterns, and discuss the problem with the doctor. At times, dealing with these behaviors can be as simple as changing the subject or redirecting the person's attention. At other times, it can be much harder to deal with these behaviors. In general, try to avoid arguing or correcting, and focus on the feelings that the person is experiencing. Sometimes providing reassurance and comfort is the best thing you can do. Be sure the person is safe and does not have access to anything he or she could use to harm anyone.

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NOTES

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RECAP FORM

Thank you for hosting a screening and discussion panel on HBO's *The Alzheimer's Project*. Please fill in the form below and return it in the accompanying self addressed envelope, via fax or email per the instructions at the end of this document. We value your feedback and use it to advance public awareness of Alzheimer's disease, so please be candid.

1. Name: _____
2. City: _____
3. Date of screening: _____
4. Number of guests attended: _____
5. Where was screening held? (e.g., community center, school, religious facility): _____
6. Was the screening hosted by an organization? If so, please provide the name of your organization: _____
7. Please provide a brief description of the event. Please include details about how you structured the screening and discussion.

Description of event:

8. How did this screening benefit your organization?

9. Comments – Please include any memorable comments from guests (attach additional pages as necessary):

10. Did you use the customizable press release? _____

11. Did any local media cover the event? If so, please specify: _____

Your name: _____ Title: _____

Phone/Email: _____

If possible, please return this form by May 12, 2009. If your screening occurs at a later date, your feedback is still valuable to us.

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