

**DISCUSSION GUIDE**

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**CAREGIVERS**

# THE ALZHEIMER'S PROJECT

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



**HBO** DOCUMENTARY FILMS

# CAREGIVERS



**Chuck and Marianne** (*Live in the Moment*)



**Marvine and Jackie** (*Until Then Keep Holding On*)



**Daphne and Jude** (*The Long Goodbye*)



**Terry and Pat and Suzanne** (*Life After Alzheimer's*)



**Nacho and Mike** (*You Can't Do This Forever*)

## INTRODUCTION

Seventy percent of people with Alzheimer's live at home and are cared for by family and friends. The physical and emotional toll is immeasurable not just for the patient, but for the caregiver as well. Through a collection of five portraits, this film shines a light on the sacrifices and successes made by people experiencing their loved one's gradual descent into dementia. This Discussion Guide includes questions designed to start a productive dialogue about coping with Alzheimer's. It also provides Caregiving Tips to help you handle many of the issues that surround this disease.

## DISCUSSION QUESTIONS AND CONVERSATION STARTERS

### THE FILM

1. Based on what you saw in the film, what are some indicators of Alzheimer's disease?
2. What are some of the frustrations experienced by those in the early stages of Alzheimer's, like Chuck?
3. Daphne says she "tries not to dwell" on the disease and Chuck says he "lives in the moment." Are they expressing acceptance or denial? Why might different individuals react differently to diagnosis or to the disease itself?

4. What are some of the ways the caregivers in this film cope with the experience? In your opinion, who copes well and who copes poorly? Why?
5. Why might people living with Alzheimer's or those caring for them resist the idea of support groups? How else might they find relief and support?
6. What signs of caregiver stress are depicted in the film?
7. How do caregivers like Jude and Jackie stay positive? What do they say keeps them going?
8. At the hospital, it appeared as though Jude received conflicting information from two members of Daphne's medical team. How would you handle this situation?
9. Do you think that Jackie feels guilty about breaking her vow to never put Marvine in a care facility? Do you think Mike felt the same sort of guilt about Nacho? What else might caregivers feel guilty about?
10. What seem to be the toughest issues for the adult children of Alzheimer's, like Nacho's son Mike and Marvine Jr.?
11. Friends and family gathered together for Marvine's 72nd birthday and his and Jackie's 50th wedding anniversary. Why might a celebration like this be important?
12. Terry's first wife, Pat, died of Alzheimer's. He and his current wife, Suzanne, now volunteer at a care center. What do you think they get out of giving back?

# THE ALZHEIMER'S PROJECT

## GENERAL

13. If you have a family history of Alzheimer's, what action might you take? When?
14. What is meant by "the long goodbye"?
15. At what stage do those diagnosed with Alzheimer's need caregiving?
16. Do you agree with Terry that, "A caregiver can't be a caregiver if he doesn't love the person that he's caring for"? How do caregivers manage to do what they do for the duration of the disease?
17. What makes caregiving an "art"?
18. In your opinion, what are the rewards of caregiving?

## KEY THEMES AND ISSUES

### *Changes in Communication*

19. What could you do to help people like Chuck or Daphne, who might struggle to find words or forget what they want to say?
20. Is it important to correct a person like Chuck if he forgets or says something odd?
21. What are some of the things that caregivers in the film did to engage their loved ones?

### *Changes in Intimacy*

22. What effect does Alzheimer's have on the relationships between those who live with the disease and the loved ones who care for them?
23. What pressures did the disease put on Terry's relationship with his first wife, Pat, who died of the disease? How did it affect Chuck and Marianne?
24. How do Daphne, Jude, Jackie, and Marvine stay connected?

### *Sleep Issues*

25. In the film, Chuck discusses his changing sleep patterns and we see Nacho experience sleep disruption in his care facility. How do Chuck and Marianne negotiate the situation? What action does Mike take to manage Nacho's condition?

26. What are the implications of sleep issues for caregivers?

### *Caring for Caregivers*

27. What are some things that caregivers can do to maintain their own health while caring for a loved one with Alzheimer's disease? Why is it important for them to do so? Chuck calls Marianne a "saint." Do you have to be "perfect" or perfectly selfless to be a caregiver?

### *Cost of Care*

28. Based on what you've seen in the film, what are some of the emotional, social and financial costs associated with Alzheimer's disease?

## 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 caring for those with Alzheimer's disease while watching this film?
- Are you interested in learning more about any aspect of caregiving?
- Do you know where to go for information and or assistance?
- Do you know where to go to find out about research studies or clinical trials?

# CAREGIVERS



## CAREGIVING TIPS

Here are some tips that can help caregivers deal with some of the issues raised in the film. 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 are really no right answers to these questions. 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 might 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 one of the most important aspects of caregiving. 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. See more about the Medic Alert® + Alzheimer's Association Safe Return® Program at the website ([www.alz.org](http://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.

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## ***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. As a caregiver, it's also important to get the support you need to deal with your own feelings about such behavior. Do what feels best for you.

## ***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 for caregivers 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.

## ***Choosing Care Facilities and Services***

Most people with Alzheimer's disease are cared for at home. However, there may come a point when caregivers are no longer able to take care of their loved one at home. Choosing a residential care facility – a nursing home or an assisted living center – is a big decision. Although difficult, you may want to gather information about services and options before the need arises so you're prepared if the time comes. It's important to understand what's available, what it costs, methods of payment, and what private insurance, Medicare, and Medicaid are likely to cover. See the resources section for more details about these issues.

## ***Self Care for Caregivers***

For most caregivers, the needs of the person with Alzheimer's Disease are the highest priority, but caregivers need care, too. Taking care of your own health is an important part of being a good caregiver. As much as possible, eat nutritious meals, make time for exercise, get plenty of rest, do things you enjoy, and get the support you need.

Accepting help when it's offered is another part of taking care of the caregiver. So, when people offer to help, it's a good idea to have a couple of suggestions ready – ask someone to prepare a meal, do some grocery shopping, or take the person with Alzheimer's for a walk or outing so that you can get a break or some rest.



# CAREGIVERS

## 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:

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8. How did this screening benefit your organization?

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

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10. Did you use the customizable press release? \_\_\_\_\_

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

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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.

**By mail to:**

Civic Entertainment Group  
Attn: Alzheimer's Project  
450 Park Avenue South  
5th floor  
New York, NY 10016

**By fax to:**  
212-426-7002

**By email to:**  
kevin.koenig@cegny.com.

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