

DISCUSSION GUIDE

GRANDPA, DO YOU KNOW WHO I AM? WITH MARIA SHRIVER

THE ALZHEIMER'S PROJECT

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



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INTRODUCTION

Families face many challenges when someone they love is diagnosed with Alzheimer's. It affects everyone in the family, in one way or another.

This film gives voice to children and young teens who experience the disease through a grandparent. We are able to see their confusion, sadness, and fear, but we also see their creativity, wisdom, and courage. They show us many ways to cope.

These discussion questions are designed to help start family and community conversations between kids and adults about the film and about Alzheimer's disease. We hope that they will bring wider understanding about the profound effects that the disease can have on individuals, families, and society as a whole.

The questions below are divided into two groups: one for grown-ups, the other for young people. At the end of the discussion guide, you will find resources that can help you learn more about the disease and what you can do.

DISCUSSION QUESTIONS AND CONVERSATION STARTERS FOR ADULTS

1. From the film, what did you notice about the way kids define Alzheimer's? Is that different from the way most adults do?
2. Maria Shriver suggests that there are many lessons that kids can teach adults about AD. What have you learned from kids about coping with Alzheimer's?
3. What did you think when Grandma and Grandpa talked to Genevieve, Liam, and Margaret? Can you imagine yourself being part of a conversation like this? What do you think parents and other grown-ups can do to help kids understand what's going on and what to expect?
4. Did you notice that the children in the film seem to hope for the best, but manage to be realistic, too? How do you think they do that?
5. Maria Shriver says that she learned to take cues from her father who has AD and not to correct him. How could you explain this to children? Are there times when you might need to correct the person with Alzheimer's?
6. How important is it for the kids to feel that they are doing something for a grandparent with AD? How do you know when it's too much for them? What do you do then?

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- 7.** In the film, both Sarah (age 15) and Daylen (age 7) have caregiving responsibilities, such as staying with the grandparent or helping with feeding. What are reasonable and age-appropriate ways kids can help with caring for a grandparent?
- 8.** In the film we see a few sudden mood swings from people with Alzheimer's (becoming angry or unresponsive). How do the kids respond? What could you say to a child or teen who experiences this?
- 9.** People with Alzheimer's sometimes become violent or aggressive. How can you ensure that everyone is safe?
- 10.** What are some of the ways children and teens enrich the lives of the grandparents with AD? Can a grandparent with Alzheimer's enrich the lives of grandchildren?
- 11.** Do you think the kids are worried about their parents as well as the grandparent with Alzheimer's? How do the parents cope with their own feelings about having a parent with Alzheimer's while taking care of their kids?
- 12.** We see a number of kids (Megan and Danielle, Alissa) visiting their grandparent in a nursing home, and these are very emotional moments. How did they cope with what they saw and felt? How is it different for young kids and the teens? Why?
- 13.** Maria Shriver says that you never get used to having a parent or a grandparent forget who you are. How do the kids in this film show us how to love someone who doesn't know who you are?
- 14.** In the film, a number of the kids talk about remembering what their grandparent was like before he or she had AD. What are some of the ways that we can help our kids to do that? What does it mean to be a "keeper of memories"?
- 15.** For other kids, like Alissa, their grandparent has always had Alzheimer's disease, and they have no memories of what the person was like before the disease. What did Alissa do to deal with this? Do you think it helped her and the rest of her family?
- 16.** Maria says Alzheimer's is difficult on every level, but that it sometimes shows the bonds of love between generations. Did you notice specific instances of that in the film?

17. Some kids in the film talk about being glad that they still have their grandparents, others feel hurt or sad that the person they knew is gone. Do you think sometimes people wish that the pain were over?

18. Did viewing this film change the way you think about AD? Do you wonder if there's something you can do about the disease?

KEY LESSONS

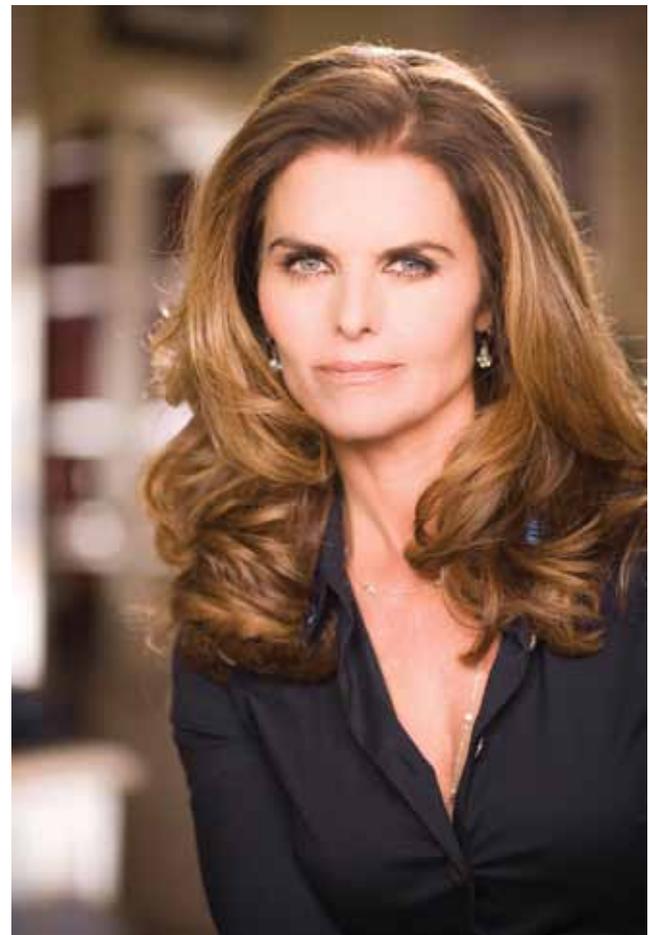
There are no silly questions you can ask about Alzheimer's.

When it comes to Alzheimer's, just go with the flow as best you can.

It's okay to be afraid of Alzheimer's.

Sometimes it's the disease talking, not your grandparent.

You can be the keeper of memories.



Maria Shriver

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CONVERSATION STARTERS FOR TALKING WITH KIDS

- 19.** What did you like best about the film?
- 20.** What was the hardest part?
- 21.** Do you have a parent or grandparent who has Alzheimer's? Do you know anyone whose parents or grandparents have the disease?
- 22.** Does this film help you understand what's going on with people with Alzheimer's and their family members? Will you treat yourself or your friend and his/her family differently after watching this film?
- 23.** Is there someone you can talk to if you're concerned about AD?
- 24.** If someone in your family has Alzheimer's disease, do you help with caregiving? What kinds of things do you do to help? How do you think you're making a contribution?
- 25.** What do you do when you feel afraid, or sad, or angry, or lonely about what is going on with Alzheimer's in your family? Do you ever feel embarrassed or guilty? Do you have family and friends that you can talk with when it's hard for you?
- 26.** Do you worry that your Mom or Dad might get the disease? Do you worry you might get it?
- 27.** If you could ask any of the children in the film a question, what do you think it would be? Can you imagine how they might answer you?
- 28.** A number of children wish that their grandparent wouldn't have AD or that a cure will be found. Who's working on curing the disease? Is there any way you or your family could help with that effort?

TIPS FOR TALKING TO KIDS ABOUT ALZHEIMER'S DISEASE

In this section, we provide a number of tips and suggestions to help parents, grandparents, and other adults prepare for talking about AD with children. Take these suggestions and adapt them for your family. Trust your heart and your own wisdom and creativity to do what seems best.

HELPING CHILDREN UNDERSTAND AD

When a family member has AD, it affects everyone in the family, including children and grandchildren. The type of relationship and the child's age should determine:

- What information he or she receives.
- How the information is presented.
- The child's part, if any, in caring for the person with AD.

Giving children information about AD that they can understand will help them. There are good books about AD for children of all ages. You can find more about these resources at www.HBO.com.

Here are some other suggestions to help children understand what is happening:

- Answer their questions simply and honestly. For example, you might tell a young child, "Grandma has an illness that makes it hard for her to remember things."
- Understand that their feelings of sadness and anger are normal, and tell them it's okay to feel this way.
- Comfort them. Tell them they didn't cause the disease. Children may think they did something to hurt their grandparent. Remind them that person with AD still loves them, but may have a hard time showing it.
- Remember that as children get older, they may need more detailed information.

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- Provide information on what they can expect in terms of what impact the disease will have such as, "Grandpa might repeat himself a lot. Just do your best to be kind and patient." Or "Grandma probably won't talk much and we may need to help feed her." This can be especially important if the child/teen hasn't seen the person with the disease in some time.

If the child lives in the same house as someone with AD:

- Don't expect a young child to help take care of the person with AD.
- Make sure the child has time for his or her own interests and needs, such as playing with friends, going to school activities, or doing homework.
- Make sure you spend time with your child, so he or she doesn't feel that all your attention is on the person with AD.
- Help the child understand your feelings. Be honest about your feelings when you talk with a child, but don't overwhelm him or her.

Many younger children will look to you to see how to act around the person with AD. Show children they can still talk with the person, and help them enjoy things each day. Doing fun things together can help both the child and the person with AD. Here are some things they might do:

- Do simple arts and crafts.
- Play music.
- Sing.
- Look through photo albums.
- Read stories out loud.

Some children may not talk about their negative feelings, but you may see changes in how they act. Problems at school, with friends, or at home can be a sign that they are upset. You may want to ask a school counselor or a social worker to help a child understand what is happening and how to cope.

Kids may also be concerned about the impact on their own parent of caring for someone with AD and not want to add to the parent's burden. If the stress of living with someone who has AD becomes too great for a child, there are several respite options, including adult day centers, additional help in the

COMMON REACTIONS AND FEELINGS THAT YOU MAY SEE IN CHILDREN AND TEENS:

- Sadness about changes in a loved one's personality and behavior.
- Confusion or fear about why the person behaves differently.
- Worry that the disease is contagious and that they will get it.
- Fear that their parents might develop the disease.
- Worry that something they said or did caused the disease.
- Anger and frustration with the need to repeat activities or questions.
- Guilt and/or anger about being short-tempered with the person.
- Jealousy and resentment because of the increased amount of time and attention that is given to the person with Alzheimer's.
- Embarrassment about inviting friends or other visitors to the house.

home or a stay in a respite care facility that might give you and your child a much needed break.

Kids who have a grandparent with Alzheimer's are often afraid that their Mom or Dad might develop the disease, too. This is a difficult question for a parent to answer because even

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science and medicine don't have all the answers. Here are a couple of things you might say:

- It is possible that someday I might develop the disease, but that time is a long way away.
- Most people who get Alzheimer's are in their 70's or 80's or older.
- Scientific research is learning more every day about the disease and is looking for ways to treat and prevent Alzheimer's. There is hope that someday there will be a cure.

In the meantime, take good care of your health and model good lifestyle choices for healthy aging generally, by eating a healthy diet, getting exercise, and treating your high blood pressure, high cholesterol, or diabetes if you have any of these conditions.

WAYS TO HELP CHILDREN AND TEENS COPE:

- Offer comfort and support.
- Provide opportunities for them to express their feelings.
- Let them know their feelings are normal.
- Educate them about the disease and encourage them to ask questions.
- Respond honestly to questions.

SOME ACTIVITIES THAT CAN HELP AND BE DONE AS A FAMILY:

- Go for a walk.
- Do household chores together, such as folding laundry, raking leaves or washing dishes.
- Listen to music, dance or sing.
- Look at old photographs.
- Read a favorite book or newspaper.
- Create a scrapbook or photo album about the person.
- Make a family tree.
- Watch a movie.
- Keep a journal together.

ESPECIALLY FOR KIDS AND TEENS

To help children and teens learn more about Alzheimer's disease and understand how it affects them, the Alzheimer's Association has a special Kids & Teens section on their website. It includes printed resources, book reviews and links to sites that explain how the brain works.

Sources:

National Institute on Aging, National Institutes of Health www.nia.nih.gov/alzheimers
Alzheimer's Association www.alz.org

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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.

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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