

A Discussion Guide for

THE FORGETTING

A Portrait of Alzheimer's



Encore National Broadcast
August 3, 2008 at 9 PM ET, check local listings

PRIME TIME EMMY AWARD WINNER

pbs.org/theforgetting

followed by

THE FUTURE OF ALZHEIMER'S
with David Hyde Pierce

A Production Of
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About the film: *THE FORGETTING: A PORTRAIT OF ALZHEIMER'S*

Based on the bestselling book by David Shenk and originally broadcast in 2004, *The Forgetting* was the first television program to tackle the entire spectrum of the Alzheimer's epidemic, from the personal tragedy to the worldwide race to stop the disease in its tracks.

In the film, three individuals and their families bring us into the intense, real-world experience of Alzheimer's disease. Gladys Fuget, still in Alzheimer's early stage, jokingly denies her memory problems even as we witness her struggling to recognize her own image in a photograph. Fran Noonan wrestles the disease's middle stage, tormented by outbursts of anger, sadness and confusion. In Alzheimer's final stage, Isabelle McKenna loses everything but the ability to sense human touch and the steadfast devotion of her family. During each stage of the illness, we witness these families' tenacity, frustration, grief and humor.

The Forgetting also offers a window into the world of Alzheimer's research. World-renown scientists share groundbreaking discoveries on the disease, and explain how and why Alzheimer's dismantles the day-to-day lives of people like Gladys, Fran, Isabelle, and their families.

As the number of Alzheimer's cases skyrockets and the research forges ahead, *The Forgetting* portrays the personal and social impact of the disease, and gives viewers reason for hope.

About this Guide: READ, DISCUSS, LEARN

This guide is based on *The Forgetting* and is intended to offer information and spur conversations about Alzheimer's. It is aimed at a wide range of audiences, and addresses issues common to all stages of the disease.

"**LEARN ABOUT IT**" pages are one-sheet overviews on specific elements of the disease. Topics include:

- ❖ **ASKING HARD QUESTIONS:** Introductory information on Alzheimer's
- ❖ **EXPECTING THE UNEXPECTED:** A stage-by stage look at the disease
- ❖ **LIVING WELL WITH ALZHEIMER'S:** Ideas to ease and enrich daily life
- ❖ **TALKING TO CHILDREN ABOUT ALZHEIMER'S:** Ways to engage and inform kids whose family members are coping with the illness

These informational pages offer a foundation for the "**TALK ABOUT IT**" section, which features discussion questions about the disease. These questions offer great "prompts" to get the conversation rolling at home viewing parties, community meetings, in classrooms, or in healthcare settings, or in more intimate situations like family discussions or even in personal journals. While this guide's content is inspired by *The Forgetting*, it can also be used independent of the film.

We hope that using this guide, including the last page's Web links to national Alzheimer's resources, will help to raise awareness, increase communication, and offer connections. To obtain *The Forgetting* DVD and companion book "The Forgetting: Alzheimer's: Portrait of an Epidemic" by David Shenk, please visit www.shopPBS.org or call 1-800-PLAY-PBS.

LEARN ABOUT IT:

ASKING HARD QUESTIONS

Do I Have Alzheimer's?

You forget where you left your keys. You snap at your spouse. You lose your train of thought in mid-sentence. Should you be worried about Alzheimer's?

As the number of people suffering from or caring for someone with Alzheimer's grows, it's almost impossible to not have some experience with the disease. It's even tougher to avoid wondering about your own or your loved ones' lapses of memory.

Everyone forgets things now and then, but Alzheimer's behaviors are more dramatic.

Someone with early Alzheimer's might be:

- Forgetful ("He repeated the same story four times today.")
- Paranoid ("She lost her wallet and blamed her daughter for stealing it.")
- Disoriented ("It's 2 A.M., and he's asking for a ride to the grocery store.")
- Moody ("He shouted at the neighbors for stepping on his yard.")
- Tongue-tied ("She calls the toaster 'that bread thing.'")
- Confused ("He's unable to perform tasks that were once simple.")

Remember: Alzheimer's isn't the only thing that can cause these symptoms. If you're concerned about yourself or others, consult a physician.

What's my risk of getting Alzheimer's?

Unfortunately, the greatest risk factor is unavoidable: old age. Nearly half of all people over age 85 suffer from Alzheimer's disease. Since one in nine baby boomers could live to be 100, compared to one in 500 in their grandparents' generation, this figure is especially sobering.

Genetics also plays a role. The most common form of Alzheimer's disease, late-onset, cannot be predicted with genetics alone. Scientists have found a gene, APOE4, that increases the likelihood for developing the disease, but it's not an absolute predictor. You can have the gene and never get Alzheimer's, and you can develop Alzheimer's without having inherited the gene.

Inherited Alzheimer's or Familial Alzheimer's is very rare, accounting for less than five percent of Alzheimer's cases. It usually strikes earlier in life and progresses more quickly than late onset.

How can I lower my Alzheimer's risk?

- *Mind your "body basics"*: Get regular exercise, and watch your weight. Avoid or treat high blood pressure. Make sleeping and resting high priorities.
- *Feed your body*: Eat your vegetables. And your fruits and whole grains. Look for foods rich in folic acid, antioxidants and vitamins B6, B12, C and E. Also, omega 3 fatty acids, like those found in fish, walnuts and flaxseed. Avoid excessive alcohol and fat.
- *Feed your mind*: Stay mentally active. Take interesting classes, study a foreign language, try music lessons. Read. Try your hand at crossword puzzles. The more challenging the material, the better.

LEARN ABOUT IT:

EXPECTING THE UNEXPECTED: STAGES OF ALZHEIMER'S

When most people think about Alzheimer's, they immediately—and perhaps only—think of memory loss. Indeed, memory and speech problems are hallmarks of early stage Alzheimer's. And as the disease progresses other behaviors can occur. Alzheimer's middle stages can often feature erratic outbursts, anxiety or depression. In the late stages, people with Alzheimer's typically have little speech ability, and normal bodily functions slowly shut down.

This is not to say that the three stages are predictable. Every individual and every family experiences Alzheimer's in a unique way. However, it's empowering for people with Alzheimer's and their families to focus on the abilities commonly retained, rather than on the abilities that are lost.

For example, during the early stages of the disease, it is not uncommon for people with Alzheimer's to be able to:

- Handle simple processes like finances
- Understand and carry on conversations
- Plan common tasks like dinner
- Navigate through familiar surroundings without help
- Recognize familiar people and places
- Explain away strange behaviors
- Read and write

As the disease progresses to the middle stage, many people with Alzheimer's can still:

- Remember things and people from long ago
- Recognize their own face
- Understand short phrases
- Read and understand singular words
- Make simple interpretations of sensory experience (something's hot, salty, loud, etc...)
- Mimic simple actions
- Carry out familiar social interactions (i.e. "Hello, how are you?")
- Walk and move without difficulty
- Make simple yes/no, either/or decisions

During late or end stages, it is still common for people with Alzheimer's to:

- Interpret and use basic body language
- Enjoy sounds, tastes, smells, sights and touch

LEARN ABOUT IT:

LIVING WELL WITH ALZHEIMER'S

Of course life is never the same after an Alzheimer's diagnosis, but it is possible to live well with the disease. People with Alzheimer's and their families suggest the following tips:

Go with the flow:

As their disease progresses and their brains change, people with Alzheimer's often have strange or irrational behavior. Accept that these personality changes are the disease, not the person. Know that Alzheimer's progresses differently for everyone. For example, one person may experience hallucinations regularly, while another never does. Some days will be seemingly normal, others will present major challenges.

Streamline:

Limit the number of things your loved one needs to remember. Take over the things that require memory or complex planning, like tracking appointments, laundry and meal-making. Seek help if these tasks become overwhelming. Check resources like "The Alzheimer's Action Plan: The Experts' Guide to the Best Diagnosis and Treatment for Memory Problems" by P. Murali Doraiswamy, Lisa P. Gwyther, and Tina Adler for additional suggestions.

Research community care options:

Know your options before you become overwhelmed. From home aides to adult day programs to assisted living, there is a range of options to explore in addition to home care and nursing homes. For help deciding what would work best for you, call the Alzheimer's Association hotline at 1-800-272-3900, or visit the Association's online CareFinder at www.alz.org.

Ask your doctor about treatment options:

What can medications do? How do we know if a medication is working? Are there any clinical trials? For more information about clinical trials, visit the National Institute on Aging's Web site at www.nia.nih.gov/alzheimers, and click 'clinical trials.'

Feed your soul:

Stay in touch with friends and family. Initiate stimulating conversations, start a debate about something that matters to you, join a faith community. Volunteer. Whatever helps you connect with others is important.

Talk about "it":

Chances are, no matter how awkward it might feel, everyone close to someone with Alzheimer's feels confused, angry, afraid, frustrated, embarrassed, exhausted, overwhelmed, lonely, and grief stricken. Discussing these feelings with each other, or with a professional, might help ease this challenge.

Talk about money:

Learn more about financial situations, and get the help you need to ensure financial affairs run smoothly and on time. Locate legal and financial documents. If certain documents, such as durable power of attorney for health care, have not yet been made, do so by contacting a certified eldercare attorney. Visit www.benefitscheckup.org to see if you're eligible for special benefits.

Create support:

If you're an Alzheimer's caregiver, you shouldn't go it alone. Seek out friends family and professionals and let them help you. Acknowledge the loss and look to the future life does go on. A rich variety of support networks are listed at www.tpt.org/theforgetting.

LEARN ABOUT IT:

TALKING WITH CHILDREN ABOUT ALZHEIMER'S

People with Alzheimer's disease and their caregivers often describe the experience as frightening, confusing and sad. If these strong emotions are reported by adults, imagine how overwhelming the experience can be for children. A formerly indulgent grandmother appears apathetic about her granddaughter's accomplishments or opinions. A grandfather becomes uncharacteristically "testy," scolding his grandkids for perceived misdeeds. These confusing and often hurtful behaviors may make children perceive themselves as "bad," and they may hide injured feelings. Even worse, some kids may simply avoid their affected loved one, ending a valuable relationship. But with communication and planning, families can help children deal with Alzheimer's. Some quick tips include:

- **Keep talking.** Explain to small children that Grandma isn't angry with them, and would really like to talk and play with them like she used to. However, her brain has an illness that makes it hard for her to do the things she used to do, and act the way she used to act. Emphasize that this illness will not happen to them (as children), but only affects older grown-ups. Underscore that you cannot "catch" Alzheimer's, as you could a cold or other illness.
- **Keep visiting.** Plan a focal point for each visit. Kids can have a "show-and-tell" time when they bring photos, artwork or even a favorite toy to discuss. These items serve as memory prompts and communication cues; even if the loved one cannot respond, assure children that they are enjoying the conversation. Suggest small chores that kids can perform for their loved one. These tasks allow children a feeling of importance and control, and provide the valuable experience of helping someone who cannot help herself.
- **Get active.** Help a child make a memory book. This book can include labeled pictures of loved ones, photos of vacations, or even advertisements from "the old days." Kids can use this book as a springboard for discussions about family. Encourage kids to sing some "oldies but goodies"; people with dementia, even if they cannot engage in conversation, can often recall old lyrics, childhood poems, etc. Have children share puzzles or blocks with their loved one, as people with Alzheimer's sometimes enjoy simple tactile kinesthetic activities.
- **Get outside.** Go for a walk, to a playground, or just sit outdoors. Talk about sounds, smells, and sights, and enjoy watching the kids play and run.
- **Get visual.** Dig out old family videos featuring weddings, parties, and other fun gatherings. These movies remind kids how their loved one "used to be," and provide a conversational prompt for the person with Alzheimer's.

Another excellent resource is the Alzheimer's Association "Just for Kids and Teens" link. Click on http://www.alz.org/living_with_alzheimers_just_for_kids_and_teens.asp to find great information and tools, all presented in child-friendly terminology, including "The Brain," "101 Activities," age-appropriate stories, videos, and more.

TALK ABOUT IT:

Discussing Alzheimer's Disease

- Are you currently concerned about you or a loved one developing Alzheimer's disease? Why? How do you feel about being tested for this risk, and what assessment resources exist in your community?
- What resources exist in your community to help develop a "care strategy," if Alzheimer's becomes or is a reality in your life?
- How do you think a caregiver feels throughout these three stages? What community resources exist to support caregivers and families?
- What has been your most profound Alzheimer-related life change? What resources do you have or need to cope with this change?
- What is your most critical "practical" concern about having Alzheimer's, or caring for someone with it? Is it money, care, housing?
- What is your most important "emotional" concern about having the disease, or caring for someone with it?
- What questions do you still have about Alzheimer's? Do others in the group have answers for these questions, or can they recommend resources?
- Recommend the best Alzheimer's resource you've discovered, and talk about why it is/was effective for you.
- What activities can you imagine sharing with someone who is currently experiencing these three stages? What expectations are fair to have of people in each stage? Can you name activities that might be too difficult or frustrating?
- What healthy habits can you incorporate into your life to decrease the Alzheimer's risk? What obstacles do you have to making these positive choices?
- What is the most difficult part of having Alzheimer's or caring for someone with the disease? What resources can you access to ease this challenge?

THE FORGETTING: A PORTRAIT OF ALZHEIMER'S

For more information on Alzheimer's, please visit:

The Forgetting
www.pbs.org/theforgetting

AARP
www.aarp.org

Administration on Aging
www.aoa.gov

Alzheimer's Association
www.alz.org

National Institute on Aging Alzheimer's Disease Education and Referral Center
www.alzheimers.org

The Alzheimer's Disease Research Center
www.alzheimer.wustl.edu

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