


A Discussion Guide for

# THE FORGETTING

A PORTRAIT OF ALZHEIMER'S



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PBS

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FIFTEEN YEARS AGO, THERE WERE APPROXIMATELY 500,000 AMERICANS WITH ALZHEIMER'S. TODAY, THERE ARE TEN TIMES AS MANY—ALMOST FIVE MILLION.

—David Shenk, author  
of *The Forgetting*

ABOUT  
**THE FORGETTING:  
A PORTRAIT OF ALZHEIMER'S**

Based on the bestselling book by David Shenk, *The Forgetting* is 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.

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*, produced and directed by award-winning documentarian Elizabeth Arledge, 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: Tuning In, Logging On, Reaching Out**

This guide is based on *The Forgetting* and is intended to offer information and spur conversations about Alzheimer's. It is intended for a wide range of audiences, and addresses issues common to all stages of the disease. We hope that using this guide will raise awareness about Alzheimer's, and ultimately act as a springboard for discussion, resource-sharing, and further study.

While this guide's content is tied to the documentary and its interactive companion Web site, it can also be used independent of the broadcast or the online presence. And again, because this guide is a "starting point," we encourage readers to search the Internet or use the highlighted community organizations for additional, more specific Alzheimer's information.

Each page addresses a common concern about Alzheimer's, and then guides users through these features:

- Learn About It: background information on the designated topic
- Talk About It: questions or suggestions for community or family discussion
- Think About It: questions for journaling or private exploration
- Link It: Web links for users to gain further experience or more information

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## ASKING HARD QUESTIONS

### Learn About It

#### *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 (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 a sure-fire 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?*

- 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.
- Mind your "body basics": Get regular exercise, and watch your weight. Avoid or treat high blood pressure. Make sleeping and resting high priorities.

### Talk About It

- 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?

### Think About It

- 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?

### Link To It

Go to [www.pbs.org/theforgetting](http://www.pbs.org/theforgetting) to learn more about the basics of Alzheimer's.

# WE KNEW SHE WAS GOING TO LOSE HER MEMORY BUT...I DON'T THINK WE WERE PREPARED FOR WHAT TRANSPIRED.

–Butch, whose sister  
has Alzheimer's

## EXPECTING THE UNEXPECTED: STAGES OF ALZHEIMER'S

### Learn About It

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:

### Talk About It

- 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?

- 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:

### Think About It

- How do you think a caregiver feels throughout these three stages? What community resources exist to support caregivers and families?

- 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

### Link To It

Go to [www.pbs.org/theforgetting/livingcenter/](http://www.pbs.org/theforgetting/livingcenter/) and explore The Living Center with someone who has Alzheimer's. The Living Center is an online collection of activities filled with interesting images and sounds that users can click and discuss, or simply enjoy.

I'M LOSING MY MIND. BUT THE ESSENCE OF A PERSON IS THEIR HEART AND I HOPE THAT AS I GROW OLDER, I'LL STILL BE ABLE TO LAUGH AND I'LL STILL BE ABLE TO HUG AND I'LL STILL KNOW LOVE.

–Fran, who has Alzheimer's

## LIVING WELL WITH ALZHEIMER'S

### Learn About It

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 be 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.

#### ***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

#### ***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 NIA Web site at [www.alzheimers.org](http://www.alzheimers.org), 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

- 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.

I SOMETIMES I FEEL THAT I FAIL TO PROPERLY COMPENSATE FOR THE FACT THAT IT'S NOT HER, IT'S THE DISEASE. AS LONG AS I REMEMBER THAT, THEN IT'S ALL RIGHT.

–Harry, whose wife has Alzheimer's

## LIVING WELL WITH ALZHEIMER'S (CONTINUED)

### ***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/](http://www.benefitscheckup.org/) to see if you're eligible for special benefits.

### ***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.

### ***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/NPD/forgetting](http://www.tpt.org/NPD/forgetting).

### **Think About It**

- 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?

### **Link To It**

For a thorough list of Alzheimer's resources, visit [www.pbs.org/theforgetting/resources/](http://www.pbs.org/theforgetting/resources/). You can search Alzheimer's links by topic or keyword to find sites that are helpful for your situation.

You can also use the Web to find the best local resources. Visit:

- The Alzheimer's Association chapter finder:  
[www.alz.org/findchapter.asp](http://www.alz.org/findchapter.asp)
- The Administration on Aging: Legal Resources  
[www.aoa.gov/eldfam/Elder\\_Rights/Legal\\_Assistance/Legal\\_Hotline.asp](http://www.aoa.gov/eldfam/Elder_Rights/Legal_Assistance/Legal_Hotline.asp)  
A list of hotlines for elder people seeking legal assistance. Those staffing the hotline will not give legal advice; rather, they give referrals to appropriate organizations or lawyers.

# HOW DO I CONVINCING MY GRANDSON THAT HIS GRANDMOTHER STILL LOVES HIM, AND THAT IT'S NOT REALLY HER FAULT THAT SHE IS THAT WAY?

–Harry, whose wife has Alzheimer's

## TALKING WITH CHILDREN ABOUT ALZHEIMER'S

### Learn About It

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 himself.
- **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.

### Talk About It

*Ask a child:*

- What questions or concerns do you have about Grandpa? Remember, there are no silly or "bad" questions.
- Can you describe your feelings when you are around Grandma? Do you feel scared, happy, embarrassed, or mixed up?
- What things do you most miss doing with the "old" Uncle Ted? What are some cool activities you might do together now? What can we draw (or sing or bake or build) for him, or what tasks can you help him do?

### Link To It

Introduce a child to the Living Center at [www.pbs.org/theforgetting/livingcenter/](http://www.pbs.org/theforgetting/livingcenter/). The Living Center is a Web site full of online activities created specially for people with Alzheimer's and their caregivers. A child (or any family member or friend) can show the site to the person with Alzheimer's as a way to engage their interest and spend quality time together.

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**For more information on Alzheimer's, please visit:**

The Forgetting  
[www.pbs.org/theforgetting](http://www.pbs.org/theforgetting)

AARP  
[www.aarp.org](http://www.aarp.org)

Administration on Aging  
[www.aoa.gov](http://www.aoa.gov)

Alzheimer's Association  
[www.alz.org/](http://www.alz.org/)

National Institute on Aging Alzheimer's Disease Education and Referral Center  
[www.alzheimers.org](http://www.alzheimers.org)

The Alzheimer's List  
[www.adrc.wustl.edu/alzheimer/](http://www.adrc.wustl.edu/alzheimer/)

The Eldercare Chat Forum  
<http://eldercare.infopop.cc/6/ubb.x>

The Alzheimer's Association Message Boards  
<http://srch.alz.org/mb/system/login.html>

*The Forgetting* video,  
DVD and companion  
book by David Shenk  
are available by visiting  
[www.shop.pbs.org](http://www.shop.pbs.org) or  
calling 1-800-ShopPBS.