THE FORGETTING

A Portrait of Alzheimer's

PBS

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PRIME TIME EMMY AWARD WINNER
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Alzheimer's Caregivers: The Hidden Second Victim

*In the PBS documentary **THE FORGETTING: A Portrait of Alzheimer's**, which premiered in January 2004, the Fugets were among the courageous families who shared their lives to help Americans better understand and cope with Alzheimer's disease. The program revealed the enormous energy, support and compassion that so many families rally to provide even as they face the frustration and the heartbreak of watching the mental and physical deterioration of a loved one. Alzheimer's disease is truly death by a thousand subtractions.*

*Now **THE FORGETTING** is back with a brand new 30-minute follow-up show, **THE FUTURE OF ALZHEIMER'S with David Hyde Pierce**. Pierce, with a panel of Alzheimer's experts who will explain and contextualize the latest research findings, emphasize the importance of addressing and treating Alzheimer's within ethnic and racial minorities, and discuss the future of Alzheimer's research and treatment.*

Gladys Fuget was one of an estimated 5.2 million Americans living with Alzheimer's disease. Harry Fuget, her husband, was the primary caregiver for Gladys, and his days and nights were filled with the demands and responsibilities of caring for her. "She's still in denial," stated Harry in 2004. Gladys had her own explanation for her memory lapses: she blamed Harry. "She maintains that the only thing wrong with her is me, if she could get rid of me she'd be in perfect shape . . . she knows where everything is except when I take and move it, so that she can't find it," he said. For Harry, it was a long journey, one that tried his love and commitment to a woman slowly slipping away. "It's frustrating, one day at a time. I sometimes 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." Some people live as many as 20 years after the first onset of symptoms, and their caregivers are often the hidden second victim.

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The Fugets, like millions of other families across the country, faced the daily emotional, physical, and financial repercussions of Alzheimer's, a disease of the brain that relentlessly destroys a person's mind and memory. Harry was distraught over the reality that Gladys is no longer resembles the active, alert woman he once knew. "The disease is robbing us of what little time remains…and it looks bleak and frightening ahead…The future is not someplace I'm madly dashing to get to." Over the past 20 years, immense progress has been made in understanding Alzheimer's disease and its risk factors. However, much remains to be done to delay the progression of the disease, prevent it and ultimately find a cure.

According to the Alzheimer's Association 2008 Alzheimer's Disease Facts and Figures, in 2007, the 9.8 million family and other unpaid caregivers of people with Alzheimer's and other dementias provided 8.4 billion hours of care. Harry, like so many caregivers, felt overwhelmed by the physical and emotional demands associated with caring for an Alzheimer's patient. "Feels like you're on a constant treadmill," he remarked. About one-third of family caregivers of people with Alzheimer's and other dementias have symptoms of depression. Caregivers often may not recognize their own needs or simply do not know where to turn for help. The Alzheimer's Association urges caregivers to recognize and take steps to reduce stress.

Taking care of yourself is one of the most important ways to be a healthy caregiver

Ask yourself ...

Are you so overwhelmed by taking care of your loved one that you've neglected your own physical, mental and emotional well-being?

If you find yourself without the time to take care of your own needs, you may be putting yourself and your health at risk.

Do you visit your physician regularly?

Be aware of what you body is telling you. Your exhaustion, stress, sleeplessness and changes in appetite or behavior should be taken seriously. Ignoring these symptoms can cause your physical and mental health to decline.

Do you accept assistance from others?

You can't do everything. Attempting to handle it all yourself will only lead to burnout, depression and resentment toward the person in your care.

Do you talk to others about your feelings?

You may think that no one understands what you are going through. Holding in your feelings, however, will only make you feel isolated and emotionally neglected.

10 symptoms of caregiver stress

1. Denial about the disease and its effect on the person who's been diagnosed
   I know Mom is going to be better.
2. Anger at the person with Alzheimer's or others, anger that no cure exists and anger that people don't understand what's going on
   If he asks me that question one more time, I'll scream!
3. Social withdrawal from friends and activities that once brought pleasure
   I don't care about getting together with the neighbors anymore.
4. Anxiety about facing another day and what the future holds
   What happens when he needs more care than I can provide?
5. Depression that begins to break your spirit and affects your ability to cope
   I don't care anymore.
6. Exhaustion that makes it nearly impossible to complete necessary daily tasks
   I'm too tired for this.
7. Sleeplessness caused by a never-ending list of concerns
   What if she wanders out of the house or falls and hurts herself?
8. Irritability that leads to moodiness and triggers negative responses and reactions
   Leave me alone!
9. Lack of concentration that makes it difficult to perform familiar tasks
   I was so busy, I forgot we had an appointment.
10. Health problems that begin to take their toll, both mentally and physically
    I can't remember the last time I felt good.

10 ways to be a healthy caregiver

1. **Get a diagnosis as early as possible.**
   Symptoms of Alzheimer's may appear gradually. It can be easy to explain away unusual behavior when your loved one seems physically healthy. Instead, consult a physician when you see signs of the disease.
2. **Know what resources are available.**
   Get in touch with the Alzheimer care resources in your community. Adult day care, in-home assistance, visiting nurses and Meals on Wheels are just some of the services that can help. Start with your local Alzheimer's Association chapter.
3. **Become an educated caregiver.**
   As the disease progresses, new caregiving skills are necessary. The Alzheimer's Association can help you better understand and cope with the behaviors and personality changes that often accompany Alzheimer's.
4. **Get help.**
   Doing everything by yourself will leave you exhausted. Seek the support of family, friends and community resources. If you're afraid to ask for help, have someone advocate for you. Alzheimer's Association support group meetings, helplines and online community are good sources of comfort and reassurance. If stress becomes overwhelming, seek professional help.
5. **Take care of yourself.**
   Watch your diet, exercise and get plenty of rest. Make time for shopping, a movie or an uninterrupted visit with a friend by taking advantage of community services like adult day care or in-home services. To learn more about the respite care services in your area, contact your local Alzheimer's Association chapter.

6. **Manage your level of stress.**
   Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, loss of appetite). Note your symptoms. Use relaxation techniques that work for you, and consult a doctor.
7. **Accept changes as they occur.**
   People with Alzheimer's change and so do their needs. They often require care beyond what you can provide on your own. A thorough investigation of care options should make transitions easier; so will the support and assistance of those around you.
8. **Do legal and financial planning.**
   Plan ahead. Consult an attorney to discuss legal and financial issues, including durable power of attorney; living wills and trusts; future medical care; housing; and long-term care insurance. If possible and appropriate, involve the person with Alzheimer's and other family members.
9. **Be realistic.**
   Know that the care you provide does make a difference. Also know that, until a cure is found, the progression of Alzheimer's disease is inevitable. Many of the behaviors that occur are beyond your control and the control of the person with Alzheimer's. Give yourself permission to grieve your losses, but also focus on the positive moments as they arise and enjoy your good memories.
10. **Give yourself credit, not guilt.**
    At times, you may lose patience and find yourself unable to provide all the care the way you'd like. Remember, you're doing the best you can. Don't feel guilty because you can't do more. Your loved one needs you, and you are there – that should make you feel proud.

Credits

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THE FORGETTING: Portrait of Alzheimer's and ***THE FUTURE OF ALZHEIMER'S with David Hyde Pierce*** are produced by Twin Cities Public Television. The executive producer is Naomi S. Boak. David Hyde Pierce is host of ***THE FUTURE OF ALZHEIMER'S***. The producer and director of ***THE FORGETTING*** is Elizabeth Arledge. The documentary is based on the book, "The Forgetting: Alzheimer's: Portrait of An Epidemic" by David Shenk. The editor is Doug Quade. Cinematography by Erich Roland. Original music is by Mason Daring. Gerald Richman is executive in charge.

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