

## **“Dementia/Caregiver Resources” compiled by Gurney Williams**

...an informal collection of information and links from the leaders of a discussion session on dementia/caregiving at the Yale Class of 1963 50<sup>th</sup> reunion on May 31, 2013

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*Please note that if you are unable to open the links below, try copying and pasting the link address into your internet browser.*

### **Caregiver health problems**

...from the Alzheimer's Association March, 2013 Alzheimer's Disease Facts and Figures

[http://sitesearch.alz.org/search?q=cache:-6yIz\\_Pkg9gJ:www.alz.org/documents/mndak/facts2013\\_fact\\_sheet.pdf+factsheet+mar+2013&access=p&output=xml\\_no\\_dtd&ie=UTF-8&lr=&client=alz&site=core\\_national\\_office&proxystylesheet=alz&oe=UTF-8](http://sitesearch.alz.org/search?q=cache:-6yIz_Pkg9gJ:www.alz.org/documents/mndak/facts2013_fact_sheet.pdf+factsheet+mar+2013&access=p&output=xml_no_dtd&ie=UTF-8&lr=&client=alz&site=core_national_office&proxystylesheet=alz&oe=UTF-8)

In 2012, 15.4 million family and friends provided 17.5 billion hours of unpaid care to those with Alzheimer's and other dementias — care valued at \$216.4 billion... More than 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high; more than one-third report symptoms of depression... Because of this toll, dementia caregivers had \$9.1 billion in additional health care costs of their own in 2012.

... from the Family Caregiver Alliance (although footnotes don't refer to any studies done after 2006):

[http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1822#73](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822#73)

An estimated 44 million Americans age 18 and older provide unpaid assistance and support to older people and adults with disabilities [including dementias] who live in the community.<sup>1</sup> The value of this unpaid labor force is estimated to be at least \$306 billion annually,<sup>2</sup> nearly double the combined costs of home health care (\$43 billion) and nursing home care (\$115 billion).<sup>3</sup> Evidence shows that most caregivers are ill-prepared for their role and provide care with little or no support,<sup>4, 5, 6</sup> yet more than one-third of caregivers continue to provide intense care to others while suffering from poor health themselves.<sup>7</sup> Studies have shown that an influential factor in a caregiver's decision to place an impaired relative in a long-term care facility is the family caregiver's own physical health.<sup>8, 9, 10, 11</sup> A substantial body of research shows that family members who provide care to individuals with chronic or disabling conditions are themselves at risk. Emotional, mental, and physical health problems arise from complex caregiving situations and the strains of caring for frail or disabled relatives. Today, medical advances, shorter hospital stays, limited discharge planning, and expansion of home care technology have placed increased costs as well as increased care responsibilities on families, who are being asked to shoulder greater care burdens for longer periods of time.<sup>12, 13</sup>

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## Caregiver mortality

**...from the American Psychological Association:**

<http://www.apa.org/pi/about/publications/caregivers/faq/risks.aspx>

...studies indicate that caregivers are at risk for increased mortality, coronary heart disease and stroke, particularly under conditions of high strain (Haley, et al., 2010; Lee, Colditz, Berkman, & Kawachi, 2003a, 2003b). There is also evidence that women take on more caregiving tasks, report more care recipient problems, and experience more distress due to caregiving than male caregivers (Pinquart & Sorensen, 2005; Yee & Schulz, 2000).

**...from an often-cited (free) article from the *Journal of the American Medical Association (JAMA)*, published in 2009**

<http://jama.jamanetwork.com/article.aspx?articleid=192209>

...active caregiver participants [in the study] who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than those [in a control group] whose spouse was not disabled.... Conclusions: Our study suggests that being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers. Caregivers who report strain associated with caregiving are more likely to die than noncaregiving controls.... The majority of caregivers are middle-aged adult children and older spouses who care for a parent or spouse with functional limitations. Although family caregivers perform an important service for society and their relatives, they do so at considerable cost to themselves. There is strong consensus that caring for an elderly individual with disability is burdensome and stressful to many family members,<sup>3-4</sup> and contributes to psychiatric

morbidity in the form of increased depression. Researchers have also suggested that the combination of loss, prolonged distress, physical demands of caregiving, and biological vulnerabilities of older caregivers may compromise their physiological functioning and increase their risk for health problems.<sup>4-5</sup>

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## **10 early signs of dementia**

**...from the Alzheimer's Association:**

[http://www.alz.org/alzheimers\\_disease\\_10\\_signs\\_of\\_alzheimers.asp](http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp)

In addition to potentially problematic signs, the list accessible through the link above includes notes on typical age-related changes that may cause you to worry more than you need to. Also please *see material below* on diagnosing dementia: [Click here to go there now.](#)

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## **Current research on dementia**

**...from the National Institutes of Health (NIH), last updated April, 2013:**

[http://www.ninds.nih.gov/disorders/dementias/detail\\_dementia.htm](http://www.ninds.nih.gov/disorders/dementias/detail_dementia.htm)

**Research on the causes of AD and other dementias** includes studies of genetic factors, neurotransmitters [packets of biochemicals that race between nerve cells], inflammation, factors that influence programmed cell death in the brain, and the roles of [other factors] and the associated neurofibrillary tangles and plaques in AD [Alzheimer's Disease]. Some other researchers are trying to determine the possible roles of cholesterol metabolism, oxidative stress (chemical reactions that can damage proteins, DNA...in the development of AD.... Some researchers suggest that people will eventually be screened for a number of genes that contribute to AD and that they will be able to receive treatments that specifically address their individual genetic risks. However, such individualized screening and treatment is still years away. ...Insulin resistance is common in people with AD, but it is not clear whether the insulin resistance contributes to the development of the disease or if it is merely a side effect. ...Several studies have found a reduced risk of dementia in people who take cholesterol-lowering drugs called statins. However, it is not yet clear if the apparent effect is due to the drugs or to other factors.... Early studies of estrogen suggested that it might help prevent AD in older women. However, a clinical study of several thousand postmenopausal women aged 65 or older found that combination therapy with estrogen and progestin substantially increased the risk of AD. Estrogen alone also appeared to slightly increase the risk of dementia in this study. (For a bit more general information on research click [here.](#))

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## Dementia basics

### ...from the National Institute of Neurological Disorders and Stroke (NINDS): Dementia Information Page

Condensed from [Dementia: Hope Through Research](#)

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### What is Dementia?

Dementia is not a specific disease. It is a descriptive term for a collection of symptoms that can be caused by a number of disorders that affect the brain. People with dementia have significantly impaired intellectual functioning that interferes with normal activities and relationships. They also lose their ability to solve problems and maintain emotional control, and they may experience personality changes and behavioral problems, such as agitation, delusions, and hallucinations. While memory loss is a common symptom of dementia, memory loss by itself does not mean that a person has dementia.

**Doctors diagnose dementia only if two or more brain functions - such as memory and language skills -- are significantly impaired without loss of consciousness.** [More on testing, from the Mayo clinic: click on <http://www.mayoclinic.com/health/dementia/DS01131/DSECTION=tests-and-diagnosis>.]

Some of the diseases that can cause symptoms of dementia are Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia, Huntington's disease, and Creutzfeldt-Jakob disease. Doctors have identified other conditions that can cause dementia or dementia-like symptoms including reactions to medications, metabolic problems and endocrine abnormalities, nutritional deficiencies, infections, poisoning, brain tumors, anoxia or hypoxia (conditions in which the brain's oxygen supply is either reduced or cut off entirely), and heart and lung problems. Although it is common in very elderly individuals, dementia is not a normal part of the aging process. [back to top](#)

## Is there any treatment?

Drugs to specifically treat Alzheimer's disease and some other progressive dementias are now available. Although these drugs do not halt the disease or reverse existing brain damage, they can improve symptoms... This may improve an individual's quality of life, ease the burden on caregivers, or delay admission to a nursing home. Many researchers are also examining whether these drugs may be useful for treating other types of dementia. Many people with dementia, particularly those in the early stages, may benefit from practicing tasks designed to improve performance in specific aspects of cognitive functioning. For example, people can sometimes be taught to use memory aids, such as mnemonics, computerized recall devices, or note taking.

## What is the prognosis?

There are many disorders that can cause dementia. Some, such as Alzheimer's disease or Huntington's disease, lead to a progressive loss of mental functions. But other types of dementia can be halted or reversed with appropriate treatment. People with moderate or advanced dementia typically need round-the-clock care and supervision to prevent them from harming themselves or others. They also may need assistance with daily activities such as eating, bathing, and dressing.

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## Caregiver help: links to key organizations

### [Alzheimer's Disease Education and Referral Center \(ADEAR\)](#)

National Institute on Aging  
P.O. Box 8250  
Silver Spring, MD 20907-8250  
[adear@nia.nih.gov](mailto:adear@nia.nih.gov)  
<http://www.nia.nih.gov/alzheimers>  
Tel: 1-800-438-4380  
Fax: 301-495-3334


### [Alzheimer's Association](#)

225 North Michigan Avenue  
Floor 17  
Chicago, IL 60601-7633  
[info@alz.org](mailto:info@alz.org)  
<http://www.alz.org>   
Tel: 312-335-8700 1-800-272-3900 (24-hour helpline) TDD: 312-335-5886  
Fax: 866.699.1246

### [Alzheimer's Foundation of America](#)

322 Eighth Avenue  
7th Floor  
New York, NY 10001  
[info@alzfdn.org](mailto:info@alzfdn.org)  
<http://www.alzfdn.org>   
Tel: 866-AFA-8484 (232-8484)  
Fax: 646-638-1546

### [John Douglas French Alzheimer's Foundation](#)

11620 Wilshire Blvd.  
Suite 270  
Los Angeles, CA 90025  
<http://www.jdfaf.org>   
Tel: 310-445-4650  
Fax: 310-479-0516

### [Association for Frontotemporal Degeneration \(AFTD\)](#)

Radnor Station Building #2 Suite 320  
290 King of Prussia Road

### [National Organization for Rare Disorders \(NORD\)](#)

55 Kenosia Avenue  
Danbury, CT 06810

Radnor, PA 19087  
[info@theaftd.org](mailto:info@theaftd.org)  
<http://www.theaftd.org>  
Tel: 267-514-7221 866-507-7222

[orphan@rarediseases.org](mailto:orphan@rarediseases.org)  
<http://www.rarediseases.org>  
Tel: 203-744-0100 Voice Mail 800-999-NORD  
(6673)  
Fax: 203-798-2291

**Family Caregiver Alliance/ National Center on Caregiving**

785 Market St.  
Suite 750  
San Francisco, CA 94103  
[info@caregiver.org](mailto:info@caregiver.org)  
<http://www.caregiver.org>  
Tel: 415-434-3388 800-445-8106  
Fax: 415-434-3508

**National Institute of Mental Health (NIMH)**

National Institutes of Health, DHHS  
6001 Executive Blvd. Rm. 8184, MSC 9663  
Bethesda, MD 20892-9663  
[nimhinfo@nih.gov](mailto:nimhinfo@nih.gov)  
<http://www.nimh.nih.gov>  
Tel: 301-443-4513/866-415-8051 301-443-8431  
(TTY)  
Fax: 301-443-4279

**National Family Caregivers Association**

10400 Connecticut Avenue  
Suite 500  
Kensington, MD 20895-3944  
[info@thefamilycaregiver.org](mailto:info@thefamilycaregiver.org)  
<http://www.thefamilycaregiver.org>  
Tel: 800-896-3650  
Fax: 301-942-2302

**Lewy Body Dementia Association**

912 Killian Hill Road, S.W.  
Lilburn, GA 30047  
[lbda@lbda.org](mailto:lbda@lbda.org)  
<http://www.lbda.org>  
Tel: Telephone: 404-935-6444 LBD Caregiver Link:  
800-539-9767  
Fax: 480-422-5434

**Alzheimer's Drug Discovery Foundation**

57 West 57th Street  
Suite 904  
New York, NY 10019  
[info@alzdiscovery.org](mailto:info@alzdiscovery.org)  
<http://www.alzdiscovery.org>  
Tel: 212-901-8000  
Fax: 212-901-8010

**Creutzfeldt-Jakob Disease (CJD) Foundation Inc.**

P.O. Box 5312  
Akron, OH 44334  
[help@cjd.foundation.org](mailto:help@cjd.foundation.org)  
<http://www.cjd.foundation.org>  
Tel: 800-659-1991  
Fax: 330-668-2474

**CJD Aware!**

2527 South Carrollton Ave.  
New Orleans, LA 70118-3013  
[cjdaware@iwon.com](mailto:cjdaware@iwon.com); [info@cjdaware.com](mailto:info@cjdaware.com)  
<http://www.cjdaware.com>  
Tel: 504-861-4627

**Well Spouse Association**

63 West Main Street  
Suite H  
Freehold, NJ 07728  
[info@wellspouse.org](mailto:info@wellspouse.org)  
<http://www.wellspouse.org>  
Tel: 800-838-0879 732-577-8899  
Fax: 732-577-8644

**National Respite Network and Resource Center**

800 Eastowne Drive  
Suite 105  
Chapel Hill, NC 27514  
<http://www.archrespite.org>  
Tel: 919-490-5577 x222

**BrightFocus Foundation**

22512 Gateway Center Drive  
Clarksburg, MD 20871  
[info@brightfocus.org](mailto:info@brightfocus.org)  
<http://www.brightfocus.org/alzheimers/>  
Tel: 1-800-437-2423

Fax: 919-490-4905

Fax: 301-258-9454

**National Hospice and Palliative Care  
Organization /Natl. Hospice Foundation**

1731 King Street

Alexandria, VA 22314

[nhpco\\_info@nhpco.org](mailto:nhpco_info@nhpco.org)

<http://www.nhpco.org>

Tel: 703-837-1500 Helpline: 800-658-8898

Fax: 703-837-1233

## **[Recent data on the toll of Alzheimer's**

**...from the Alzheimer's Association March, 2013 Alzheimer's Disease Facts and  
Figures**

**[http://sitesearch.alz.org/search?q=cache:-6yIz Pkg9gJ:www.alz.org/documents/mndak/facts2013\\_fact\\_sheet.pdf+factsheet+marsh+2013&access=p&output=xml\\_no\\_dtd&ie=UTF-8&lr=&client=alz&site=core\\_national\\_office&proxystylesheet=alz&oe=UTF-8](http://sitesearch.alz.org/search?q=cache:-6yIz Pkg9gJ:www.alz.org/documents/mndak/facts2013_fact_sheet.pdf+factsheet+marsh+2013&access=p&output=xml_no_dtd&ie=UTF-8&lr=&client=alz&site=core_national_office&proxystylesheet=alz&oe=UTF-8)**

Among 70-year-olds with Alzheimer's, 61 percent are expected to die within a decade....Dementia is the second largest contributor to death among older Americans, second only to heart failure....Between 2000 and 2010, the number of people dying of heart disease dropped 16 percent. The number of deaths from Alzheimer's increased 68 percent. [back to top](#)]

### **What research is being done?**

The National Institute of Neurological Disorders and Stroke (NINDS) and other institutes of the National Institutes of Health (NIH) conduct research related to dementia in laboratories at the NIH and also support additional dementia research through grants to major medical institutions across the country. Current research focuses on many different aspects of dementia. This research promises to improve the lives of people affected by the dementias and may eventually lead to ways of preventing or curing these disorders.

#### **NIH Patient Recruitment for Dementia Clinical Trials**

- [At NIH Clinical Center](#)
- [Throughout the U.S. and Worldwide](#)
- [NINDS Clinical Trials](#)

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**Caregiver help: Set Up Power of Attorney and other documents *now***

...from the National Institute of Aging

<http://www.nia.nih.gov/alzheimers/publication/legal-and-financial-planning-people-alzheimers-disease-fact-sheet>

A **Durable Power of Attorney for Finances** names someone to make financial decisions when the person with Alzheimer's disease no longer can. It can help people with the disease and their families avoid court actions that may take away control of financial affairs...

### Advance Directives for Health Care

Advance directives for health care are documents that communicate the health care wishes of a person with Alzheimer's disease. These decisions are then carried out after the person no longer can make decisions. In most cases, these documents must be prepared while the person is legally able to execute them.

A **Living Will** records a person's wishes for medical treatment near the end of life. It may do the following:

- specify the extent of life-sustaining treatment and major health care the person wants
- help a terminal patient die with dignity
- protect the physician or hospital from liability for carrying out the patient's instructions
- specify how much discretion the person gives to his or her proxy (discussed below) about end-of-life decisions

A **Durable Power of Attorney for Health Care** designates a person, sometimes called an agent or proxy, to make health care decisions when the person with Alzheimer's disease no longer can do so. Depending on State laws and the person's preferences, the proxy might be authorized to:

- refuse or agree to treatments
- change health care providers
- remove the patient from an institution
- decide about making organ donations
- decide about starting or continuing life support (if not specified in a living will)
- decide whether the person with Alzheimer's will end life at home or in a facility
- have access to medical records

A **Do Not Resuscitate (DNR) Order** instructs health care professionals not to perform cardiopulmonary resuscitation if a person's heart stops or if he or she stops breathing. A DNR order is signed by a doctor and put in a person's medical chart.



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## Caregiver coaches

### **Kathie Nitz**

Recommended by Gurney Williams  
who found her helpful in making long-term  
care decisions.

<http://www.kathienitz.com/>

203-578-5244

[kathie@kathienitz.com](mailto:kathie@kathienitz.com)

She's in Connecticut but conducts phone  
sessions @ \$150 for a single session,  
discounts for multiple sessions. An initial phone  
consultation is free.

### **Diana Waugh**

Recommended by a classmate.

[www.waughconsulting.info](http://www.waughconsulting.info)

Her book *I Was Thinking*, about how to talk  
with people with dementia, is  
available through her website (\$12).

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## Contact Info for discussion leaders

Charlie Soule: [chassoule@aol.com](mailto:chassoule@aol.com)

Gurney Williams: [gurnout@westnet.com](mailto:gurnout@westnet.com)

Eleonora Tornatore-Mikesh: [etornatore@alz.org](mailto:etornatore@alz.org)

Maria Tomasetti: [mtomasetti@alz.org](mailto:mtomasetti@alz.org)

**Alzheimer's Association 24/7 Helpline 800-272-3900**

[www.alz.org](http://www.alz.org)

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