

THE FORGETTING

A Portrait of Alzheimer's



Outreach Tool Kit

Introduction

Alzheimer's disease touches nearly every American family, wiping away vast stores of personal memories and human connections. It is a reality 20 million Americans live with today, and a prospect the rest of us must prepare for—for ourselves and our loved ones.

The Forgetting provides a wonderful opportunity to reach out to the core PBS audience with useful and important information. The centerpiece of this two-hour PBS prime time special is a 90-minute documentary, followed by a customizable half hour follow-up program. Complementing the broadcast, *The Forgetting's* Web site will distill the thousands of Internet resources about Alzheimer's disease into a simple, easy-to-use Web site that includes *The Living Center*, the first on-line activity center for Alzheimer's patients and their families. This project is designed to help people better understand this disease, and face their personal fears about Alzheimer's. *The Forgetting* is poised to touch and affect millions of lives.

To help you in designing your local effort, this tool kit provides:

- background project information
- project contacts
- the program treatment and a description of the half hour follow-up
- a menu of outreach activity options
- promotional resources (to be made available throughout the project).

We know your outreach successes have been built on fruitful local partnerships as well as support and teamwork within your station. *And Thou Shalt Honor* and *On Our Own Terms* partners and coalitions might provide a solid foundation on which to build local efforts. In addition, *The Forgetting's* national project partners' state and local offices, affiliates, grantees and Web sites will provide valuable expertise, resources and networks to help extend the reach and impact of this project.

We hope you will find this kit provides you with just enough information to get ideas flowing and connects you to helpful organizations and resources to make your local effort a memorable one.

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Overview

In winter 2004, PBS will present Twin Cities Public Television's *The Forgetting: A Portrait of Alzheimer's* as a two-hour National Program service special. The centerpiece is a 90-minute documentary offering an all-encompassing look at a disease that 95% of Americans feel is a serious national problem. The prime time national broadcast, based on David Shenk's critically-acclaimed book, will weave together powerful portrayals of families with the science of this awesome disease, its imprint on human history, and the current race to find a cure. Following this powerful portrait of Alzheimer's will be a localizable half-hour show designed to answer practical questions and point audiences to valuable resources.

The Forgetting outreach and promotional plans will encompass a variety of local-regional-national activities and partnerships, many beginning long before and lasting long after the television program airs on PBS. By definition, localized activities will vary significantly from one community to the next. Our goal is to help PBS stations create the best possible Alzheimer's outreach they can for their particular community. And we'll do so not by defining those efforts, but by providing advice, compelling material and committed national partners.

Key elements of these national-local activities will include:

Connecting each station with powerful local partners. Many of our national partners have local chapters or offices, with dedicated staff and volunteers working daily with the Alzheimer's community. Where available, we encourage you to link with these organizations to help you plan and implement joint outreach and educational efforts, individually tailored to the needs of your community.

Furnishing on-air, print and outreach resources, including:

- a nationally-produced follow-up program with cutaway options for localizing resource and outreach information
- viewers' guides
- an extensive Web site designed to provide users with easy access to the most up-to-date information and resources as well as a one-of-a-kind technological innovation for Alzheimer's patients and caregivers, called the *Living Center*
- educational materials available from outreach partners

Building on the relationships of earlier PBS outreach efforts, including *And Thou Shalt Honor* and the Bill Moyers' *On Our Own Terms* series on death and dying. Many stations have told us they would welcome the opportunity to continue these successful relationships.

The challenges and needs raised by Alzheimer's disease are enormous, both in the immediate term, and for our future as individuals, as families and as a society. We applaud you for your willingness to get involved. Your station and its project partners have the opportunity to help your community understand and face this disease together.

Partners/Project Contacts

MasComm Associates (outreach)

2828 Marshall Court
Suite 101
Madison, WI 53705

Phone	608.236.0674
Fax	608.236.0252
E-mail	info@mascomm.net
Web Site	http://www.mascomm.net/

Key Contacts

- Karen Hodgkiss, Consultant, 608.836.7484 (Central time), khodgkiss@mascomm.net
- Roselle Kovitz, Consultant, 425.743.4401 (Pacific time), roselle@mascomm.net

MasComm Associates specializes in fostering media and community collaborations. Clients include public and commercial television and radio, non-profit organizations, foundations, businesses and government-related agencies.

Serving as the national communication office for *Sound Partners for Community Health*, a program of the Benton Foundation funded by The Robert Wood Johnson Foundation, MasComm Associates provides technical assistance to 97 public radio stations and nine television stations working within their communities to develop programming and outreach that focuses on local health care problem-solving and partnership-building.

MasComm Associates' experience in the development and implementation of community engagement campaigns includes conducting training in collaboration and project management, performing needs assessments, writing project materials and developing action plans. We assist media clients in identifying community leaders and organizing citizens to achieve project goals.

Partners/Project Contacts

TPT/Twin Cities Public Television (production)

172 East Fourth Street
Saint Paul, MN 55101
Station Resource Web Site

fax 651.229.1570

<http://www.tpt.org/NPD/forgetting>

Key Contacts

- Kristin Pederson, Outreach Specialist, kpederson@tpt.org (contact via e-mail only)
- Ann Sunwall, Senior Outreach Manager, asunwall@tpt.org (contact via e-mail only)
- Erika Herrmann, Outreach Grant Administration, eherrmann@tpt.org (contact via e-mail only)
- Naomi Boak, Executive Producer, 651.229.1125 (Central time), nboak@tpt.org
- Erika Stenrick, Associate Producer, 651.229.1484 (Central time), estenrick@tpt.org

TPT/Twin Cities Public Television is a prominent producer of national programs for PBS. TPT productions have been honored with over 300 awards, including 25 regional and national Emmys, the duPont-Columbia Commendation, two Peabody Awards, an Academy Award nomination and awards at the Chicago, New York and Tokyo Film Festivals.

TPT's acclaimed productions have included *Hoop Dreams*, the Peabody winner and documentary classic that Roger Ebert named the "Number 1 film of the 1990s." Other TPT national productions include another Peabody winner, *Liberty! The American Revolution*, and *American Photography: A Century of Images*, a three-part series whose innovative Web site was lauded by the French newspaper *Le Monde* as one of the best arts Web sites in the world.

Most recently, TPT produced *Benjamin Franklin*, one of the most acclaimed shows of PBS' 2002 Fall Season. TPT productions also include the children's science series, *DragonflyTV* in its third season, and *Right on the Money* in its fifth season.

Partners/Project Contacts

Kelly & Salerno Communications (publicity)

71 Arch Street
Greenwich, CT 06830

Phone	203.863.1000
Fax	203.863.1010

Key Contacts

- Olivia Dupuis, 203.863.1006 (Eastern time), olivia@kellysalerno.com
- Karen Salerno, 203.863.1002 (Eastern time), karen@kellysalerno.com

Kelly & Salerno Communications specializes in advancing public awareness of social issues through powerful branding, strategic partnerships and high-impact integrated communications campaigns. The firm has particular expertise in raising public awareness of critical healthcare issues.

For the Bill Moyers multipart series, *On Our Own Terms: Moyers on Dying* in September 2000, Kelly & Salerno managed a national campaign that included extensive media penetration, as well as organizational promotion through dozens of medical, legal, religious, and governmental agencies. Last fall, the agency continued to handle healthcare-related projects with the PBS special on caregiving, *And Thou Shalt Honor*, as well as a program on the implications of reproductive technologies and genetic testing.

Partners/National Organizations

AARP

601 E. Street NW
Washington, DC 20049

Phone	202.434.2277
Toll-free	800.424.3410
Web Site	http://www.aarp.org

Description

AARP is a nonprofit membership organization dedicated to addressing the needs and interests of persons 50 and older. Through information and education, advocacy and service, they seek to enhance the quality of life for all by promoting independence, dignity and purpose. To bring that vision to life, AARP focuses efforts and resources in four areas: 1) Health and Wellness; 2) Economic Security and Work; 3) Long-term Care and Independent Living; and 4) Personal Enrichment. AARP celebrates the attitude that age is just a number and life is what you make it.

Role

AARP boasts staffed offices in every state, the District of Columbia, Puerto Rico and the U.S. Virgin Islands. State offices and their Web sites may be located at <http://www.aarp.org/statepages/>. Via the state sites, you can find local AARP charters serving your community. An AARP chapter is a group of national AARP members who formally organize through the Association, that is a non-government, non-partisan, non-profit community service organization.

With the depth and breadth of their national, state and local membership, AARP is a natural partner for *The Forgetting* outreach activities. Whether it is participating in a town hall meeting, leading a book club discussion, attending a speakers' series or helping staff a booth at an information fair, AARP members should be considered as either participants or volunteer helpers for any activity.

As the incidence of Alzheimer's disease approaches epidemic stages, AARP is poised to promote physical activity for healthy aging while preparing individuals for independent living, long-term care and end-of-life care.

Resources

AARP's Web site spans a vast array of topics, such as Grief & Loss, Health & Wellness and Life Answers. Information and resources are provided in Spanish at <http://www.aarp.org/espanol/>.

Caregiver information is located at <http://www.aarp.org/confacts/health/carerresource.html>. This includes a discussion board, called Caregivers Circle, that provides strategies that help relieve the overwhelming sense of isolation that many caregivers face daily.

Partners/National Organization Administration on Aging

Administration on Aging
1 Massachusetts Ave., NW
Washington, DC 20201

Phone 202.619.0724
E-mail AoAInfo@aoa.gov
Web Site <http://www.aoa.gov/>

Description

The Administration on Aging (AoA), an agency in the U.S. Department of Health and Human Services, is one of the nation's largest providers of home and community-based care for older persons and their caregivers. Their mission is to promote the dignity and independence of older people, and to help society prepare for an aging population. Created in 1965 with the passage of the Older Americans Act (OAA), AoA is part of a federal, state, tribal and local partnership called the National Aging Services Network, which provides assistance and services to older individuals and their families in urban, suburban and rural areas throughout the United States.

Role

AoA oversees the National Family Caregiver Support Program (NFCSP) and the Alzheimer's Disease Demonstration Grants to States Program, among others. The NFCSP, established as part of the Older Americans Act Amendments of 2000, provides funding to states based on a proportionate share of the 70+ population. States, working in partnership with area agencies on aging and other service providers, are required to provide:

- information to caregivers about available services
- assistance to caregivers in gaining access to supportive services
- individual counseling, organization of support groups and caregiver training
- respite care
- supplemental services for caregivers

To find services in your community, call the Administration on Aging's Eldercare Locator at 800.677.1116 or access it via <http://www.eldercare.gov/>.

The mission of the Alzheimer's Disease Demonstration Grants is to expand the availability of diagnostic and support services, with a particular focus on serving ethnic minorities, low income, rural Alzheimer's families and persons with developmental disabilities and Alzheimer's disease. Currently, the Alzheimer's Demonstration Program is funding 33 different states to develop models of care for persons with Alzheimer's disease, and to improve the responsiveness of the home and community-based care system to these individuals and their families. Stations that are also interested in targeting these populations or providing similar outreach activities may wish to view project summaries at http://www.aoa.gov/alz/bg/bg_s_current.asp.

Resources

Through the AoA's Alzheimer's program and AoA's Alzheimer's Resource Room Web site <http://www.aoa.gov/alz/>, families, caregivers and professionals can find information about Alzheimer's disease, caregiving, working with and providing services to persons with Alzheimer's and where to turn for support and assistance. In the caregivers section, they have fact sheets and brochures in English, Spanish, Chinese and Russian. Also, there is an extensive on-line manual for caregivers at <http://www.aoa.gov/wecare/default.htm>.

Partners/National Organizations Alzheimer's Association

225 North Michigan Avenue
Suite 1700
Chicago, Illinois 60601-7633

Phone	312.335.8700
Toll-free	800.272.3900—24 hr Contact Ctr
Fax	312.335.1110
E-mail	info@alz.org
Web Site	http://www.alz.org/

Description

The Alzheimer's Association is the world leader in Alzheimer research and care. Having awarded \$136 million in research grants, the Association ranks as the top private funder of research into the causes, treatments and prevention of Alzheimer's disease. Through its national network of chapters, the Alzheimer's Association offers a broad range of programs and services for people with the disease, their families and caregivers and represents their interests on Alzheimer-related issues before federal, state and local government and with health and long-term care providers.

Typical programs and services offered by local chapters include telephone helplines for general information and in-depth care consultation, community education and support groups. In addition, some chapters offer special programs such as funding of local researchers, assistance to people with Alzheimer's who live alone, rural and/or multicultural outreach and training programs for families and professionals.

One unique service is the Association's *Safe Return* program, which assists in the identification of and safe, timely return of individuals with Alzheimer's who wander off and become lost. Since the program began in 1993, nearly 100,000 individuals have registered for *Safe Return* nationwide. The program has facilitated the recovery of more than 7,500 individuals to their families and caregivers.

Role

Alzheimer's Association's chapters are natural partners for developing a locally produced program to follow the 90-minute documentary, and for awareness and outreach activities. Chapters can provide content experts, connections to local resources, and volunteers for awareness and outreach activities. To contact the Alzheimer's Association chapter in your community, call 800.272.3900 or go to <http://www.alz.org/findchapter.asp>.

Resources

The Association also provides extensive resources.

- For fact sheets, newsletters, resource lists and a glossary of terms, go to <http://www.alz.org/ResourceCenter/ResourceCenter.htm>.
- For information on the *Safe Return* program, go to <http://www.alz.org/ResourceCenter/Programs/SafeReturn.htm>.

Note: A variety of the Association's materials are available in Spanish, Chinese, and Korean. Translation and interpretation services are available for callers who do not speak English through the Association's toll free number 800.272.3900.

Partners/National Organizations

Delta Society

580 Naches Avenue SW Suite 101
Renton, WA 98055-2297

Phone	425.226.7357
Fax	425.235.1076
E-mail	info@deltasociety.org
Web Site	http://www.deltasociety.org/

Description

Delta Society is the leading international resource for the human-animal bond. Delta Society has validated the important role of animals for people's health and well-being by promoting the results of research to the media and health and human services organizations. The goals of the Delta Society are to:

- expand awareness of the positive effect animals can have on human health and development
- remove barriers that prevent involvement of animals in everyday life
- expand the therapeutic and service role of animals in human health, service and education

Role

Delta Society's *Pet Partners* Program trains and screens volunteers and their pets for visiting animal programs in hospitals, nursing homes, rehabilitation centers, schools and other facilities. Over 6,400 *Pet Partners* teams now operate in all 50 states and four other countries, helping more than 900,000 people each year. Delta's national network links volunteers with facilities in their communities that request visiting pets and helps *Pet Partners* contact facilities to begin visits in new locations. Stations may be interested asking Delta Society to create an event around therapy animals or to speak on this topic. There also may be opportunities for *Pet Partners* to appear at other outreach events, especially intergenerational activities or those targeted toward caregivers and/or patients, to create a unique and memorable experience.

Resources

Delta Society's Web site <http://www.deltasociety.org/> has a great deal of information about the health benefits of animals, as well as excellent definitions of terms such as therapy animals, service animals, animal-assisted activities and animal-assisted therapy. For more information about *Pet Partners*, contact Cora at 425.430.2361 or CoraB@deltasociety.org or Dianne at 425.917.1114 or DianneB@deltasociety.org.

Partners/National Organizations

Faith in Action

National Office	Phone	336.716.0101
Wake Forest University School of Medicine	Toll-free	877.324.8411
Medical Center Boulevard	Fax	336.716.3346
Winston-Salem, NC 27157-1204	Email	info@fiavolunteers.org
	Web Site	http://www.fiavolunteers.org/

Description

Faith in Action is an interfaith volunteer caregiving program of The Robert Wood Johnson Foundation. Faith in Action makes grants to local groups representing many faiths who volunteer to work together to care for their neighbors who have long-term health needs, including Alzheimer's disease. Founded on the ideal of community volunteerism of neighbors helping neighbors, Faith in Action has expanded to more than 1,000 interfaith volunteer caregiving programs across the country since 1984.

Role

The grass-roots volunteerism practiced by Faith in Action programs makes it an excellent partner for public television outreach efforts. Local programs are active in all 50 states, Puerto Rico, and the US Virgin Islands, making it possible for members of the community who have long-term health needs to maintain their independence for as long as possible.

Congregations often act as extended families of those living with Alzheimer's disease. Faith in Action volunteers come from churches, synagogues, mosques and other houses of worship, as well as the community at large. They help those in need by:

- providing respite for full-time family caregivers
- picking up groceries or running errands
- providing rides to medical appointments
- providing friendly visits (talking and listening)
- reading or helping to pay bills

You can find a local program at <http://www.fiavolunteers.org/programs/index.cfm>.

Resources

Faith in Action serves its mission through hands-on work at the local level. However, the national office offers a wide variety of technical assistance to help sustain the local programs, so that they can serve their communities for many years to come. For interested communities, Faith in Action offers start-up grants for up to \$35,000 during a 30-month period to help organize new coalitions for volunteer caregiving. Funding information is available at <http://www.fiavolunteers.org/funding/index.cfm>.

Partners/National Organizations

NIA Alzheimer's Disease Education & Referral Network (ADEAR)

ADEAR Center
P.O. Box 8250
Silver Spring, MD 20907-8250

Toll-Free 800.438.4380
Fax 301.495.3334
E-mail adear@alzheimers.org
Web Site <http://www.alzheimers.org/>

Description

The U.S. Congress created the Alzheimer's Disease Education and Referral (ADEAR) Center in 1990 to "compile, archive, and disseminate information concerning Alzheimer's disease" for health professionals, people with AD and their families, and the public. The ADEAR Center is operated as a service of the National Institute on Aging (NIA), part of the Federal Government's National Institutes of Health. The NIA conducts and supports research about health issues for older people, and is the primary Federal agency for Alzheimer's disease research.

Role

The NIA currently funds 29 Alzheimer's Disease Centers (ADCs) and three Affiliate Centers at major medical institutions across the U.S., located in the following states:

Alabama (1)	Arizona (1)	Arkansas (1)	California (6)
Georgia (1)	Illinois (2)	Indiana (1)	Kentucky (1)
Maryland (1)	Massachusetts (2)	Michigan (1)	Minnesota (1)
Missouri (1)	New York (4)	North Carolina (1)	Ohio (1)
Oregon (1)	Pennsylvania (2)	Texas (2)	Washington (1)

Find the nearest center at <http://www.alzheimers.org/adcdir.htm>. For patients and families affected by Alzheimer's disease, many of these centers offer:

- diagnosis and medical management
- information about the disease, services and resources
- opportunities for volunteers to participate in drug trials, support groups and clinical research projects, among other programs

For a station's outreach project, ADCs and Affiliate Centers may make available researchers or other professionals to participate in speakers' series, town hall meetings or the broadcast half hour follow-up show.

Resources

The ADEAR Center has a staff of specialists available to assist with:

- answering questions about Alzheimer's disease;
- providing free publications about symptoms, diagnosis, related disorders, risk factors, treatment, caregiving tips, home safety tips and research (some materials are available in bulk, free of charge; check their Web site)
- referrals to local supportive services
- Spanish language resources
- clinical trials information
- information about the latest and most promising research and drug trials
- literature database searches for further research and reading
- training materials, guidelines and a newsletter for health care and caregiving professionals

Resources

Treatment for the 90-Minute Documentary

Based on the extraordinary best-selling book by author David Shenk, *The Forgetting* is the first television program ever to tackle the entire spectrum of the Alzheimer's epidemic – the first-hand tragedy, the rising numbers, humankind's age-old fascination with dementia and worldwide effort to find a cure.

Three victims and their families bring us up-close and personal to the intense, real-world experience of Alzheimer's disease. Early stage victim Gladys Fuget jokingly denies problems with her memory, while we watch it visibly slip away. She cannot remember what year it is, nor can she recognize her own image in a photograph. Fran Noonan wrestles with the middle stages of Alzheimer's, tormented by uncontrollable outbursts of anger, sadness and confusion. Late in the disease, Isabelle McKenna is robbed of everything but the ability to sense human touch and the presence of a family who stands by as she nears the end. It has been a "long goodbye," a journey they have been on for 13 years. We get inside these families' compelling caregiving experiences and witness their tenacity, frustration, grief and humor.

Science itself is the fourth dramatic character in *The Forgetting*. The documentary follows the trials and triumphs of researchers battling Alzheimer's on the front lines. Dr. Steven DeKosky and his team conduct breakthrough scientific tests, while Dr. Rudy Tanzi, a pioneer in the field of genetics, tells of groundbreaking discoveries that may help pinpoint the cause of Alzheimer's. The experts make the research palpable and real, explaining in down-to-earth terms how Alzheimer's dismantles the day-to-day lives of Gladys, Fran and Isabelle.

Amidst the touching stories and passionate research, a thread of history, art and literature meanders gracefully throughout the film and gives context to the maddening world of Alzheimer's. Commentary from David Shenk explains how dementia has so wholly captured the human imagination, intriguing countless great minds, from Aristotle to Shakespeare to Dickens.

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

Resources

Overview of the 30-minute Follow-Up Show

Hosted by David Hyde Pierce, star of NBC's *Frasier* and committed advocate in the fight against Alzheimer's Disease

The follow-up show will be an opportunity for those affected by or curious about the disease to find answers to their big questions. Hosted by David Hyde Pierce, the show will feature top Alzheimer's experts from around the nation. They will outline what you need to know to live well with someone who has Alzheimer's and where you can turn for help. The network of resources available to people with Alzheimer's and their families is incredible. This informative, follow-up show will raise awareness of those resources and connect people with the help they need.

Stations have the option to either broadcast the show as-is, localize it, or create their own follow-up show.

Resources Web Site

Whether you're afraid of getting Alzheimer's or have already been touched by the disease, *The Forgetting* Web site is a place to find reassurance, actionable ideas and answers to the big questions...

What's it like to have Alzheimer's?

See the disease through the eyes of those who have it. Get up close and personal with how the disease progresses from early to late stage.

Who's at risk?

Attend a crash course in current Alzheimer's wisdom. Find out why the disease is soaring to epidemic proportions, what the risk factors are and whether or not you can protect yourself.

What's normal? What's not?

Take a humorous look at some common memory mishaps, and consider the difference between those "senior moments" and the real signs of dementia.

How do we live well with Alzheimer's?

Gain insight from those who have successfully lived with and loved an Alzheimer's victim. Share your own lessons from the front lines, and use our "planning ahead" feature to reduce overwhelming anxieties about the future into a simple to-do list.

What can we do together?

Make a date with someone who has Alzheimer's, and explore *The Living Center*, a virtual 1950's living room together. This first-of-its-kind online experience has been developed for *The Forgetting* at M.I.T.'s Media Lab. Hear what's playing on an old-style radio, flip through a vintage Sears catalog, create flower arrangements and discover countless ways to enjoy each other's company.

In addition to the site's rich content, search our database of recommended Alzheimer's links to find exactly what you need. From research sites to public policy groups to discussion boards, *The Forgetting* Web site is a one-stop shop for what you need to know.

Resources

Frequently Asked Questions

Updated May 21, 2003

Can we include staffing costs in our budget for grant funds?

Yes, staffing costs are allowed. Be mindful, however, that we are looking for the biggest bang for the buck. If staffing costs take up a large portion of your budget at the expense of your programming and/or outreach effort, your proposal will not be as competitive.

Must the follow-up show be aired consecutively with the documentary?

Yes, in its premiere broadcast. We will allow for flexibility in repeat broadcasts.

What is the format for the programs? Is it several episodes, and how long is the program/each episode?

The first 90 minutes is a major, high-end documentary, giving a comprehensive look at the disease, its effect on us and the race for a cure. The final half-hour will be an informative, studio-based production designed to answer questions and provide local and national resources. We will produce a national version of the follow-up in which local stations can easily insert their local and regional resource information. We are also encouraging stations to produce their own local half-hour follow-up show in conjunction with our partner outreach organizations, in lieu of the national half-hour.

When and how will the follow-up program be available to us?

It will be fed prior to the national broadcast date both as a whole and in segments to allow you to build a local program that fits your needs. It will be produced in September or October and will be fed to stations at the end of October to allow you time to work with it.

Can I get a preview reel of *The Forgetting*?

We can send you a copy on DVD of the clip that was shown at the NCO Conference. Because of certain rights issues, it cannot be duplicated, and can be used only to present to your partners. In the coming months, a rights cleared version will be available for wider distribution on the station resource Web site.

Will the program and viewer's guide be translated into Spanish?

Many of the materials available from our national partners are produced in other languages, including Spanish. We are looking into the possibility of having the viewer's guide available in Spanish. It is doubtful that the broadcast itself will be translated.

Local Outreach Activities

Town Hall Meeting

A town hall meeting allows an open discussion about Alzheimer's, its impact on communities, tools and resources available to cope with it as well as an exploration of changes needed to better care for those concerned about getting the disease, those diagnosed with the disease and their caregivers.

Goal

Hold an information-based, solution-oriented community discussion on Alzheimer's disease, support services available for those coping with it and services still needed.

Target Audiences

- Citizens
- Health care professionals
- Civic leaders
- Business leaders
- Educators
- Insurance providers
- Clergy
- Social workers
- Employers
- Caregivers

Sample Agenda

- Introduce topic and reason for the town hall meeting
- Show clips of *The Forgetting*
- Introduce panelists
- Ask audience members to share why they came and their concerns about Alzheimer's
- Panel presentations
- Audience/panel questions and answer session, where issues of concern are recorded and provided to the appropriate local service providers
- Summarize
- Evaluation

Tips

- We encourage stations to broadcast the meeting via radio, to allow phone-in questions and comments.
- AARP or Alzheimer's Association volunteers may be available to staff phone lines.
- Hold the meetings before the broadcast to build interest in the program.

Potential Partners

- AARP
- Alzheimer's Association
- Area Agencies on Aging
- Care Facilities
- Caregiving Groups
- Faith In Action coalitions
- National Institute on Aging Research Centers
- Public radio station

Local Outreach Activities

Alzheimer's Information Fair

Hosting an Alzheimer's Information Fair is an excellent way to reach out to members of general public that you might not reach in other ways. While this is one of the more labor-intensive outreach activities, it might be the most rewarding, as you are able to directly connect people to resources. You may only want to undertake this if you have a committed partner who is already planning such an event.

Goal

Reach a broad audience to inform and educate people about the disease, while building interest in the broadcast.

Locations

Target Audiences

- | | | |
|---|---|---|
| • Shopping malls | → | General public |
| • Schools | → | Faculty and staff, students and their families, neighbors |
| • Community centers | → | Members of the neighborhood |
| • Theaters | → | General public |
| • Major employers | → | Employees |
| • Churches, Synagogues, Mosques | → | Congregation members |
| • YMCAs, health & fitness centers | → | Employees, members |
| • Hospitals, independent living facilities, nursing homes | → | Medical staff, patients, visitors |

Potential Booths

- *The Forgetting* booth with clip reel, literature and computer with Web site demonstration of *The Living Center*, the first on-line activity center for Alzheimer's patients and their families
- Medical professionals on hand to discuss warning signs, diagnosis, stages, etc.
- Memory games to attract interest
- Caregiver support program resources and representatives
- Financial planners to discuss strategies and resources available for AD patients and families
- Legal professionals to discuss Durable Power of Attorney, will and other legal matters
- Mental health professionals
- Therapy and companion animals and their owners or trainers
- Information on nursing homes and day care centers that cater to patients with dementia

Potential Partners

- AARP
- Alzheimer's Association
- Delta Society
- Faith in Action
- Caregiver groups and centers
- Medical community

Local Outreach Activities

Book Clubs & Reading Groups

One challenge with increasing awareness of Alzheimer's disease is that the subject is difficult for many people to face. Working with local libraries to promote *The Forgetting* to book clubs and reading groups may make the subject more approachable, as people have the opportunity to share their reactions and fears with others.

Goal

Increase overall awareness of David Shenk's book *The Forgetting, Alzheimer's: Portrait of an Epidemic* within the community to stimulate interest in the broadcast. Reach an audience that might not be reached through public television alone. Reduce fear and apprehension about this disease within the community.

Target Audiences

- Baby boomers
- Senior citizens
- Caregivers and family members

Tips

- Send out a letter to a list of prospective organizations, describing the book and broadcast, offering to help coordinate and publicize this activity for a book club or reading group. Follow up with a telephone call or personal contact to finalize arrangements.
- Make available contacts from local Alzheimer's or caregivers organizations to attend meetings upon request.
- Provide a sign-in sheet to track number of participants.
- Provide an evaluation form to get feedback on the topic and handouts with resource organizations and contact numbers for questions and concerns.
- Use radio to promote reading groups or to facilitate discussions. Explore the possibility of a radio interview with David Shenk.

Potential Partners

- Bookstores
- Employers
- Libraries
- Public radio
- University faculty centers

Local Outreach Activities

Electronic Meeting Places

The internet provides a wealth of information for caregivers and Alzheimer's patients. It also functions as a two-way communications vehicle, providing a way for people to communicate at a time and place that is most convenient, which is especially important for family caregivers. Through on-line tools like message boards and discussion groups, users can interact with others in their community or in a "virtual" community who are in similar situations.

Goal

Direct people to on-line communities of individuals coping with this disease, to help reduce isolation and despair through connections with others.

Target Audiences

- Caregivers
- Alzheimer's patients
- Families of Alzheimer's patients

Potential Activities

With listservs and email, promote national or local on-line newsletters, message boards, listservs, newsgroups and discussion groups, such as:

- The Alzheimer's Association's newsletters and message boards
 - People may sign up for Progress, the Alzheimer's Association's monthly electronic newsletter which provides the latest research information, advances and caregiver tips and/or subscribe to Advances, the Association's quarterly newsletter at <http://www.alz.org/ResourceCenter/ByType/AssociationNewsletters.htm>.
 - Join message boards to share thoughts and experiences with others touched by the disease at <http://srch.alz.org/mb/system/login.html>.
- E-mail support groups, including those specific to Alzheimer's disease, are listed on the ElderCare On-line's Caregiver Support Network page at <http://www.ec-online.net/Community/Activists/can.htm>.
- An Alzheimer's newsgroup is available at news:alt.support.alzheimers

Potential Partners

- Alzheimer's Association
- Medical professionals to answer questions, if developing local group
- Web host, if developing local group

Local Outreach Activities

Outreach to Employers & Employees

According to the Family Caregiver Alliance, “Between one-third to one-half of all caregivers are also employed outside the home. Working caregivers sacrifice leisure time, and often suffer stress-related illnesses. Negative effects on working caregivers include time lost from work, lower productivity, quitting a job to give care, lost career opportunities and lower future earnings. Eventually, some 12% quit their jobs to provide care full-time.” Among employees who remain on the job, work disruptions due to caregiving responsibilities result in significant productivity losses. Activities that raise awareness of these issues will help employers and employees understand the effects of caregiving on workers and the workplace and how best to support these unsung heroes.

Goal

Increase awareness of how caregiving affects employees, their co-workers, and company productivity. Encourage employers to offer planning information, resources, support programs/services and benefits (such as flex time, in-house support groups and lunchtime seminars) that address caregiving issues.

Target Audiences

- Employees who care for a loved one or who are worried about caring for a loved one in the future
- Human resource managers
- Training and development professionals
- Employers and business owners
- Employee-assistance professionals

Potential Activities

- Work with partners, such as the Alzheimer’s Association, to provide speakers to the Chamber of Commerce, local chapters of American Society for Training and Development, human resource or management groups and major employers, to brief members on the impact of caregiving on employees, the workplace and company productivity. Provide information on support services and model programs that benefit employees, their families and the bottom line. Address issues such as long-term care and financial planning.
- Work with local employers to arrange brown bag lunch seminars where affected employees can learn about community support services.
- Identify and publicize businesses that support caregivers through company policies and programs.

Potential Partners

- Administration on Aging
- Alzheimer’s Association
- American Society for Training and Development
- Chambers of Commerce
- Major employers

Local Outreach Activities

Respite Activities

The stress of caregiving can take its toll on caregivers' health, finances, career and family relationships. Respite activities provide caregivers a way to relieve stress, network and just get away from it all.

Goal

Provide time and space for caregivers to relax, get support and/or express themselves through creative activities.

Target Audiences

- Caregivers

Potential Activities

- **Night out for caregivers.** Plan an evening diversion, such as screening a comedy or classic movie and providing refreshments.
- **Creative arts activities or classes.** Enlist art, crafts or creative writing instructors to lead one or a series of classes that allow caregivers to explore their creative side and/or create a remembrance of their loved one. Other ideas include:
 - Collage
 - Memory pillow
 - Scrapbook
 - Telling/recording life stories
 - Creative writing
 - Cooking classes
 - Music therapy
- **Tai chi, chi gong or yoga.** Draw on local tai chi, chi gong or yoga instructors to provide a special series of classes for caregivers to help reduce stress.
- **Massage.** Bring in massage therapists to provide seated massages at special caregiver events.
- **Creative Caregiving Club.** Host a support group for caregivers that will let people discuss unique strategies for living well with Alzheimer's. Groups can e-mail their best or wildest ideas and stories to *The Forgetting's* Web site, and, if chosen, they will be posted.

Tips

- Use local resources, such as an art theatre to host a night out for caregivers.
- Promote activities through local partners, businesses, senior centers, retirement homes and assisted living facilities' and other caregiver or family support groups.
- Use the activities to pitch a story to local media to promote the role of caregivers and the need to support their efforts.
- Provide adult and/or child care services to free up caregivers to participate.
- Include pet therapy at any of these events.
- Many respite activities can be intergenerational.

Potential Partners

- Alzheimer's Association
- Delta Society
- Faith in Action
- Caregiving Groups
- Child care centers
- Community colleges
- Community theaters
- Local art theatre
- Local musical organizations
- Senior centers

Local Outreach Activities

Speakers' Series and/or Educational Presentations

Getting accurate information and knowing where and how to access resources can help us face and address fears about Alzheimer's disease.

A speakers' series or educational presentations can be targeted to a variety of audiences, including organizations that have regularly scheduled membership meetings. These organizations frequently look for new speakers and fresh topics. Schedule prior to the broadcast to promote *The Forgetting*.

Goal

Provide accurate, helpful information on Alzheimer's disease including diagnosis, treatment, living with the disease and caregiver support to those coping with or concerned about the disease.

Target Audiences

- General adult audience
- Baby boomers
- Senior citizens
- Caregivers
- Youth

Potential Topics

- General Information
 - What is Alzheimer's disease?
 - The difference between normal forgetting and Alzheimer's
 - Lowering your risk for Alzheimer's
 - Benefits of early diagnosis
 - After the diagnosis
 - Stages of the disease
- Living with Alzheimer's
 - What it's like to have Alzheimer's, using stories from the Web site or having early-stage patients discuss their experience with the disease
 - Managing at home or in a care facility
 - Enjoying a person's remaining abilities rather than focus on disabilities, using *The Living Center* for interaction
- Caregiving
 - Dealing with stress
 - Caring for the caregiver
 - Long distance caregiving
 - Balancing work and caregiving demands
 - Family communication
 - Communicating with Alzheimer's patients
 - Benefits of music, art and other therapies
 - Coping with aggressive behavior
 - Tackling financial and legal issues when a loved one has Alzheimer's
 - Long-term grieving

Local Outreach Activities

Speakers' Series and/or Educational Presentations *(continued)*

- Coping
 - Communicating effectively with your physician.
 - Benefits of therapy or companion animals for Alzheimer's patients (Note: This would be a good intergenerational event for adults and teenagers.)
 - Using on-line resources for support, recordkeeping and connection with others, showcasing *The Forgetting* Web materials for caregivers, patients and teens.

Tips

- Identify your target audience, topics and potential speakers.
- When securing a location for the event(s), make sure parking is available and that it is accessible to those with disabilities.
- Consider piggybacking speaker events on existing meetings, such as civic, church, or senior groups, public service sororities or fraternities.
- Promote the series beyond the media to senior centers, churches, support groups, businesses or other entities.
- Invite representatives from community organizations.
- Provide informational handouts.
- Promote *The Forgetting*.
- Record responses to the series by providing short evaluation forms.

Potential Partners

- Alzheimer's Association
- Delta Society
- Faith in Action
- NIA Alzheimer's Disease Centers
- Area Agencies on Aging
- Caregiving Groups
- Fraternity/sorority collegiate and alumni groups
 - Delta Sigma Theta <http://www.deltasigmatheta.org/> – This sorority is a public service organization that strives to confront the problems of African Americans and, hence, all Americans. Their programs address education, health, international development, and strengthening of the African American family. A workshop titled "Women, African Americans, and Alzheimer's Disease" was presented to a standing-room-only audience at this organization's 2002 national convention. The response was very positive, giving an indication of possible future partnerships.
 - Sigma Kappa Sorority <http://www.sigmakappa.org/index.html> – In 1984 Sigma Kappa responded to an increasingly critical problem facing older Americans by adding Alzheimer's disease research and education to its philanthropic activities. Research grants are made each year to universities and other institutions actively engaged in the fight against Alzheimer's disease.
 - Tau Kappa Epsilon Fraternity <http://www.tke.org/> – This fraternity has established a partnership with the Alzheimer's Association to donate its fundraising proceeds to the association's Ronald and Nancy Reagan Research Institute, established by the Reagans to advance research into the disease. See <http://www.tkecentral.net/alz/> for more information on this project.
- Rotary, Optimists or similar civic groups

Local Outreach Activities

Activity Evaluation

- Start with the end in mind. When you develop your goal(s) and strategies, have a clear vision of what you want to happen as a result of your plan. Be specific. A well written goal is realistic, specific and measurable. Consider your strengths and limitations when designing your project to insure your goals are achievable.
- Correlate your evaluation strategy with your goal(s). Using your goals and strategies to create a checklist for your evaluation process will keep you focused on your intended results. When creating evaluation questionnaires, clarify each question you ask, insuring it is clear and will yield the kind of information you seek. Below are some sample questions for informational events:
 - How useful was (NAME EVENT) in helping you better understand (INDICATE THE TOPIC COVERED HERE, such as Alzheimer’s disease; the difference between normal forgetting and Alzheimer’s; Alzheimer’s prevention strategies; stages of the disease; etc.)?
1 – not useful; 2 – somewhat useful; 3 – useful; 4 – very useful
 - What was the most valuable thing you learned?
 - What do you plan to do as a result of the information you received at this event?
- **Identify what information you need.** Limit your evaluation to the information you, your partner or funder(s) will find useful and which will provide a snapshot of the impact of your effort.
- **Determine how you will gather your data.** Quantitative measures are the most direct way to determine impact. They might include the number of people attending events, requesting information or calling a hotline. But numbers alone don’t paint a complete picture of your project’s reach and can be misleading. For instance, counting those who attend events or participate in call-in programs may count people who attended or called more than once. Qualitative measures, which can provide the stories behind the statistics, include using pre- and post-questionnaires to demonstrate greater awareness of or changes in perspectives on an issue, fielding surveys or using evaluation forms at special events. If you distribute resource materials, consider including a self addressed, stamped post card to encourage feedback on how they were used.
- Build in proof of performance strategies. Envision how you plan to document your proof of performance. Many stations have found proof of performance spots a good way to reinforce their role as a resource in the community. Envision what story you’d like to tell as a result of this effort. What results will you share with your community?