

Advances

Alzheimer's Disease: *It's About Our Families*

It is heartbreaking to watch a loved one battle Alzheimer's disease.

It is hard to accept that an otherwise healthy-looking individual can no longer perform even the most routine daily activities, such as feeding, bathing, grooming and toileting. If this is baffling for an adult, imagine how confusing it may be for a young child or teenager, even embarrassing or frightening.

This issue of *Advances* explores the effects of Alzheimer's disease on children and young adults and offers guidance for adults and for kids on how to approach and cope with this disease.

Throughout the issue are accounts of young people coping with Alzheimer's disease.

Understanding and Helping Our Children

Alzheimer's disease is a family disease — it changes the lives of everyone it touches. Being an adult who has a parent with Alzheimer's is hard, but being a child in a family experiencing Alzheimer's is perhaps more difficult. Relationships are redefined, the individual with the disease becomes more dependent on family members, and the person they once knew is lost to the effects of the disease. A long grieving process ensues. And younger family members are often going through many other physical and developmental changes at the same time.

How Kids Feel

Confused, hurt, scared. These are some of the reactions children have disclosed when asked about Alzheimer's in their families.

While adults may be focused on complex issues concerning care, financial plans and treatment decisions, young children may be more narrowly focused. Grade-school-age children who participated in an art therapy workshop presented by the Alzheimer's Association Northern California and Nevada Chapter made these observations about their grandparents with dementia. The children noted that grandparents: didn't remember things, didn't look the same, couldn't read books or do small things with their hands and asked questions that didn't make sense.

And possibly most hurtful of all, they didn't remember the child.

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Articles include:

- A story about a 10-year-old who has memorialized her grandfather by raising funds for Alzheimer research.
- Poems by young adults who have seen the ravages of Alzheimer's up close.
- Programs that assist parents and educators in explaining Alzheimer's to children.
- An annotated list of books and web sites to help children and adults learn more and understand more.

Growing Up With Alzheimer's

Three years ago, Al Rhodes-Wickett was 55 and a minister in the United Methodist Church. His wife, Sharon, was a minister in the church, as well. He had two great kids: 18-year-old Rachel and 15-year-old Ben. They lived in a nice home, and he enjoyed wonderful relationships with his family.

"Dad was always a creative thinker," said Rachel. "So when the symptoms started, we said, 'Oh, it's just Dad being Dad.'" But the loss of memory, the disorientation began to be bothersome. The Rhodes-Wickett family, who live in the Westwood area of Los Angeles, saw doctors, added up all the signs and came up with a worst-case diagnosis. "It was Alzheimer's," said Rachel.

"My first thought was pure fear. I was horrified because I knew the disease had no cure. Then I felt some relief that

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Understanding and Helping Our Children

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The New Parental Relationship

When a grandparent has dementia, a child also has to deal with a different kind of relationship with his or her parents. As the parents' caregiving responsibilities increase, they often have less time to spend with their children. According to Bonnie Beam, who has conducted a workshop for children and parents in the Greater Illinois Chapter, the most discussed concern among children was feeling left out by their parents. Children may feel they are "competing" with the grandparent for the parents' attention and time.

These feelings may be more apparent if a grandparent moves in with a family. Sheelagh McGurn notes in *Under One Roof: Caring for an Aging Parent* that most families need to do some shifting when a person joins the household. They may need to change or share a bedroom. Meals may be planned around the grandparent's needs. The children may have to be aware of new routines, safety measures and quiet times.

Children as Care Partners

This transition often results in new responsibilities, too. Adolescents, in particular, may have to do more work around the house or assist with care. Teens have reported that they:

- Have less time for homework, extracurricular activities and friends.
- Do not talk about home life with their friends or teachers.
- Have expressed embarrassment about a grandparent's or parent's behavior.
- Have not wanted to bring friends home.

In spite of these challenges, adolescents who have taken on responsibilities have also reported some positive outcomes, such as feeling needed or valued, understanding the needs of people with illnesses and having a closer relationship with the parent who is the primary care partner.

For More Information

A free parent's guide, "Helping Children and Teens Understand Alzheimer's Disease," is available. Call 800.272.3900 and ask for item # ED209Z.



What Can Parents Do ?

- Explain in age-appropriate terms what is happening to the person with dementia.
- Give children opportunities to express their feelings.
- Answer their questions honestly.
- Help them identify activities they can do with the individual with dementia.
- Be aware of signs of anxiety or stress, such as changes in behavior, poor performance in school or withdrawal from family and friends.
- Inform teachers and school counselors of the impact Alzheimer's disease is having on your family.
- Encourage children to participate in support groups.

What Can Educators Do ?

- Include Alzheimer's disease and related disorders in science, health and social studies curricula.
- Develop intergenerational community services projects with nursing homes or adult day care facilities.
- Contact your local Alzheimer's Association chapter about support groups and programs for children and adolescents.
- Recruit students or a student organization for an Alzheimer's Association Memory Walk team.
- Invite specialists in research, care and public policy to an awareness forum about issues facing older adults.
- Participate in Brain Awareness Week, a program for K-12 students sponsored by the Society for Neuroscience: www.sfn.org.

Fifth Graders Learn Lessons about the Head and the Heart

Reading, writing and arithmetic are alive and well in Julie Kingsley's fifth-grade class in North Yarmouth, Maine. But each spring, her students close their books and open their hearts and minds to residents experiencing Alzheimer's living at BaySquare, a nearby senior living community.

"Becoming Friends: Elders Volunteering in the Classroom" is a program collaboratively developed by Susan Levandoski, RNC, BSN, geriatric nurse specialist at the University of New England's Division on Aging in Biddeford, Maine, in concert with Julie Kingsley. A service-learning project, the program connects academic learning with community volunteer experience. There are three lessons on Alzheimer's disease and aging, followed by three classroom visits from the elders.

"For elders with Alzheimer's, this is an opportunity to get outside of their living situation, to volunteer and to contribute as a productive member of society," says Levandoski. "The children learn about the disease and about tolerance, patience and empathy." Elders selected to participate are in the early to advanced stages of the disease, are mobile and possess some language skills to communicate and interact with the kids.

Once a week for three consecutive weeks, four elders team up with small groups of kids. There are poetry-writing exercises that fuel creativity with the adults while fulfilling writing and language requirements for the children. They also engage in art, classroom meetings, recess and reminiscence activities.

"Once, a woman's memory was triggered, and she shared with the kids that she used to be a teacher," says Levandoski. "The BaySquare staff didn't even know about this. A memory window opened up for her through this experience."

Levandoski also reports that within the last two years, kids who have grandparents with Alzheimer's have spoken up and have shared their own experiences with the class, adding to the program's richness.

For More Information

If you would like more information about "Becoming Friends: Elders Volunteering in the Classroom," e-mail Susan Levandoski at slevandoski@une.edu.

For information on the curriculum, see page 9.

Dubuque Girl Turns Pain in the Neck into Donations

Molly Schmerbach, a 10-year-old fifth-grader at Table Mound Elementary in Dubuque, Iowa, started small, giving her mom a neck massage to relax her at the end of a long day. "I'd pay her a quarter," said Molly's mom, Joan Schmerbach. "She set up a little business on the computer, recording her income and keeping track of her accounts."

Neck rubs for mom turned into a great way for Molly to earn donations for Memory Walk. "My grandpa had Alzheimer's," Molly explained. "He had it for 12 years before he died, so I never knew what he was

really like, but we were good friends. I wanted to make money to help them find a cure for Alzheimer's."

Molly's massage business grew to include her school counselor, and then her principal bought neck rubs for all of the school office staff. The effort raised some \$50 toward Molly's Memory Walk donation.

Next, the enterprising young woman wrote a story about her grandfather for a teachers' writing conference. She submitted the story to be printed in her church's weekly bulletin and that Sunday set up a small table outside the

sanctuary to receive donations. She collected about \$150 for Alzheimer's. She also received additional donations from neighbors and friends, bringing her total to about \$300.

"Molly was very close to her grandfather," explained Joan Schmerbach. "They had a wonderful camaraderie, with lots of teasing and give-and-take. Even when my dad's disease progressed, Molly would sit with him, sometimes reading to him and sometimes just holding his hand. Raising money for Alzheimer's research has been really important to her."

Preserving Precious Memories

Spread across the kitchen table are ticket stubs, newspaper clippings and postcards. Black-and-white photographs spill from an old shoebox. Gathering these mementos for the pages of a scrapbook are a grandmother and her granddaughter.

As they look through the photos, grandma finds a recipe card. She begins to tell her granddaughter how she made brownies for good report cards brought home by her children.

This memory is significant because grandma has dementia. The disease will eventually erase her priceless memories and her ability to communicate. But for now, the memories and experiences she can recall are being preserved in this scrapbook. Once completed, it will provide a lasting testimony to her life and serve as a reminder of who she is.

Scrapbooking is a hands-on activity a child or teen and an individual in the early stages of dementia can enjoy working on together. It is a positive experience that can bring the generations closer by expressing their creativity and sharing their stories. The person may not remember a recent event, but he or she may recall a childhood birthday or a favorite vacation taken as a young adult. An older child or teen can help the person with dementia capture these memories.



How to Scrapbook

Gather photos that cover the person's lifetime, including pictures of childhood, parents and siblings, spouses, grandchildren, residences over the years, family pets, celebrations or a favorite hobby or activity.

- Go through the photos, label them and talk about them with the person.
- Choose a recent photo of the person for the front page of the album.
- Organize the inside contents by topic, for example, "school days," "my first job" and "family life."
- Ask the person to write a sentence or two underneath the photos once they are mounted on pages. If this is too difficult, talk about the photos and memories and fill the pages in together.
- Use large letters and simple language.

Scrapbooking tips provided by Creative Memories, a national sponsor of the Alzheimer's Association 2003 Memory Walk.

Creating a Memory Box

Typically, a memory box is a small collection of items used to commemorate a person or event, which is tucked away for future reference. For people with Alzheimer's and their families, a memory box can become a valuable repository for objects — cards, letters, ribbons, pressed flowers, toys, articles of clothing and so on — that trigger memories, laughs, sadness and even joy any time of the year.

A box may be centered on a theme: autumn, for example, might contain leaves (to touch and to feel the crunch, to recall Friday night high school football games); small pumpkins (to hold and roll around in the hands to generate thoughts about Halloween and pranks); candy corn (a typical taste of autumn); pictures of colorful trees taken during a New England fall color tour; or a famous quote or relevant line of Scripture. Used as an activity with an Alzheimer's patient and his or her family, a memory box creates a lasting, personal legacy in honor of the person with Alzheimer's.

Memory box tips provided by the Greater Dallas Chapter.

Poems from Children Affected by a Loved One With Alzheimer's

Grandparents Live on Forever *Not Quite an Elegy*

by Jaime Puente Jr., Bishop, Texas,
for his grandmother, who has Alzheimer's, and for his
grandfather, who is also going through a lot

My grandparents are going through a great deal
and some of it isn't possible to heal
Alzheimer's and diabetes are two that exist
coping with it is hard to resist
It's hard to see loved ones suffer but showing them
love and care will make them tougher
They sometimes cry
wish that all this can be one big lie
But a lie this is not
because they are going through a whole lot
They've helped my parents raise me
for in my heart they'll stay for eternity
Through all the laughter and the tears
for my grandparents, I'll always be here
I'll do whatever I can
to lend a helping hand
I understand what lies ahead
but staying strong I'll do instead
My grandparents deserve to be happy as can be
keeping them in your heart is the best key.

by Trevor Smith, Wheeling, W. Va.,
for his grandmother

I walk under the awning, on
eighty-eight feet of old and gray cement—
leads to florid doors of wood and glass,
much like a hotel.
I enter. The clean scent
trying to veil linens and quick decay
invades my nose and throat and slightly
turns my stomach.
I exit the foyer,
fix on a grin, walk down the hallways. I pass
pairs of listless eyes that sometimes flicker,
igniting a wave,
until I find her—
head perched in blue-lined hands, body
slumped within a wheel chair, and her swollen
ankles dangle.
I sit close to her,
close to keep her attention. My thumb rubs
across the thin, loose skin over her knuckles
until false worries steal her stare and force
her hands into wringing.

Time passes.
After the fourth or fifth assurance
of her mother's good health, I kiss her
floppy cheek and say in a clear voice
that I love her.
The same drooping
eyes see the same young man walk quickly by,
eager to breathe deep again. The car
starts with a sigh
and tires slightly squeal.
But during the silent drive home, another
sigh escapes, and the emerging
forearm veins subside.
I realize the two
broken hips, stained teeth, absence of where
and how she once found her worth, do not
plague her now.
She steadily dies
to reality, a difficult departure, and slowly
awakens to the second of May,
1952. She fries bacon and looks
to mountains under a light layer of sun.

Pa-Paw

by Heather Adam, Clarksville, Ind.,
for her grandfather, George Calvin Hargett

I see my Pa-Paw sitting there
He drips and drools, but doesn't care
He's tied onto his Geri chair
It's hard to see him thus...

Yet I still visit Pa-Paw, though my visits aren't long
And there he sits, asleep and all alone
To wake him up, I shake him. He's confused and very tired
I look into his eyes—and I am known!

I wonder if he knows it's me
I try to kiss him tenderly
He swats and tries to wiggle free
It's hard to see him thus...

He smiles! Ah, Yes!!! He sees me!
Father God, please hear this prayer:
"For a moment, keep his little light turned on"
So I smile back! "I love you Pop," I try to let him know
In a flicker of an instant—he is gone.

His room is empty: walls are clean
At first I thought it cold and mean
I hate that smell: the strong chlorine
It's hard to see him thus...

And so I pray...
My Father, God, who came to save the lost
Who sent The Lamb down here—despite the cost?
If it is right for me to pray this prayer
I hope you meet him in his Geri chair.

For More Information

To submit a poem, short story
or artwork for possible posting
on our web site, e-mail your
entry (attachments must be
Microsoft Word documents) to
expression@alz.org. Please
keep your entries to a maximum
of 500 words. We reserve the
right to edit for clarity and length.

Daycare Invites Children and Seniors to Work Together

The ONEgeneration Daycare facility in Van Nuys, Calif., offers a daily program that crosses generations and touches lives. “We have 110 adults (90 percent of whom have stroke-related dementia or Alzheimer’s) and 86 children. Several times each day, they interact with each other in meaningful ways,” said Jennifer Tiller, director of Adult Daycare. “We start with the idea that every person, even those suffering from late-stage Alzheimer’s, can experienceself worth and can accomplish things. We emphasize what these people *can* do, not what they *can’t* do anymore.”

ONEgeneration is true to its name: Seniors and children interact in meaningful ways several times each day.



The program includes a daily schedule of seven structured activities that enrich the lives of both groups. These activities not only exercise the heart, they help both groups exercise their bodies and minds.

“All activities are developmentally appropriate for both groups,” said Job Baird, director of marketing for the agency, which is located in the San Fernando Valley. “Even the infants

get involved because seniors provide rocking care at naptime.”

Intergenerational programming is such a success because seniors’ and children’s needs are reciprocal in nature. While a senior needs to nurture, a child needs to be nurtured. A senior needs to leave a legacy, and by doing so gives a child a much-needed connection with the older generation.



Educating Children: Normal Aging vs. Alzheimer’s Disease

The Northeastern New York Chapter of the Alzheimer’s Association uses its Alzheimer’s School Program (ASP) to educate children and teens on the normal aging process versus the effects of dementia. Since September 2000, the ASP, designed for students in grades K-12, has been presented in more than 60 schools in the chapter’s 17-county service area.

Featuring interactive age-stimulation and communication exercises, as well as discussions, task-breakdown

activities and Association videos and brochures, the curriculum reinforces the fact that while we all experience physiological changes as we age, not everyone will be afflicted with Alzheimer’s.

“We feel children are the silent ‘victims’ of Alzheimer’s,” says Trudi Cholewinski, the chapter’s program director. “Programs specifically targeted to children directly impacted by the disease have been lacking, as has outreach that provides a deeper knowledge

of aging and dementia. We’re making a huge impact in educating children and teens on dementia and aging issues.”

Cholewinski adds that the ASP’s benefits include an increase in chapter volunteers and interest in participating in Memory Walks. The chapter also hopes to develop a support group for children and teens as an outgrowth of the program.

Growing Up With Alzheimer's

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we at least knew what was happening to Dad. And finally, I was just scared... for myself. I wondered whether I would end up with Alzheimer's."

After Rachel consulted with a home medical book, she was really upset. "The book used terms like 'invariably fatal,'" she said. "So I went to my mom, who was great. She was open and honest about everything. We talked about everything we might expect and the changes we anticipated. It made facing all this easier." To learn how to deal with the diagnosis, Rachel and her mother read books on the subject together, talked about Alzheimer research and tried to find additional resources. (For a list of annotated books and other resources for young people, see Kid's Corner on page 8.)

Then reality set in. Rachel stopped inviting friends over because she didn't want her father to embarrass himself. "The first time Dad tried to cook a meal and failed, I cried I was so sad," said Rachel. "We had another major milestone when he lost his driver's license."

Each member of the family had to change to accommodate the diagnosis. Rachel spent two years at a community college ("so I could live at home and help"), transferring last year to Scripps College in Claremont, Calif. She is majoring in psychology and intends to get her master's in social work, with the objective to work as a counselor. "Mom had to change, too. She likes everything in its place. Well, she's had to learn how to relax when

Dad puts away all the kitchen pots, pans and other stuff in the wrong places. My brother Ben got depressed but learned how to ask for help and is doing very well now," said Rachel.

Rachel has succeeded in learning to live with Alzheimer's by talking a lot, especially to her father. "We talk when we get angry at each other, and we *do* get angry. Then I find out he is angry, too, angry at his disease and what's happening to him." Her family has also honed a sense of humor. "You could become depressed if you looked at every progression of the disease as a major disaster. It makes it easier to laugh about things and to know that others are going through the same ordeal."

The family signed up for the Alzheimer's Association Safe Return program

because "now that he can't drive, he likes to take buses around the city. We try to let him do things like that because so much has been taken away from him." On the other hand, Al Rhodes-Wickett has not lost his musical ability. He is still writing music and lyrics for a musical, and he plays the piano expertly.

Rekindling old memories has helped both Rachel and her father. "One day, Mom pulled out a big box of old pictures. Seeing Dad remember and enjoy the 'old days' during their courtship and honeymoon made me less afraid of Alzheimer's. He has had a great life. This disease is just another part of his life. And I know I can have a great life, too."



The Rhodes-Wickett family at an Alzheimer's Association Los Angeles Chapter fund-raising event (left to right): Ben, Rachel, Sharon and Al.

Kid's Corner: Books and web site resources for children and young adults

Books and videos are useful when explaining complex concepts, such as Alzheimer's disease, to children.

These resources may help children understand Alzheimer's a little better and see they are not alone in their situation. Books and other resources can provide an opportunity for parents and other adults to bring up the disease and start a discussion.

For a more complete listing of informational and educational resources, please visit our web site's Resource Center at www.alz.org or call 800.272.3900 and ask for the Green-Field Library to request a resource list.



Grades 0-3: Fiction

Altman, Linda Jacobs.

Singin' with momma Lou.

New York, N.Y.: Lee & Low Books, Inc., 2002.

Nine-year-old Tamika uses photographs, school yearbooks, movie ticket stubs and other mementos to try to restore the memory of her grandmother, who has Alzheimer's disease.

Ballman, Swanee.

The stranger I call Grandma:

A story about Alzheimer's disease.

St. Cloud, Fla.: Jawbone Publishing Corp., 2001.

Andrew and his family learn what they need to do to make life tolerable for everyone when Grandma is diagnosed with Alzheimer's.

Frantti, Ann.

Grandma's cobwebs.

Clifton Park, N.Y.: Dagney Publishing, 2002.

Claire's parents teach her facts about Alzheimer's disease. They don't, however, pay attention to how Claire is feeling about the changes in her grandmother's behavior. The book introduces the concept of the three R's of Alzheimer's disease: Relax, Remember, Respect.

Glass, Sue.

Remember me? ¿Te acuerdas de mi?

Green Bay, Wis.: Raven Tree Press, LLC, 2002.

This bilingual tale centers on a girl whose grandfather has Alzheimer's disease.

Gosselin, Kim.

Allie learns about Alzheimer's disease: A family story about love, patience and acceptance.

Plainview, N.Y.: JayJo Books, 2002.

When Allie's grandmother is late for their monthly outing, Allie's mother goes to check on her at her home. We see the process the family goes through from noticing early symptoms to diagnosis and treatment and finally education.

Thurston, Dorie.

Thank you for the thistle.

White Stone, Va.: Dorie Books, 2001.

This is the story of Great Aunt Nellie, who has Alzheimer's, and her feathered friends.

Grades 4-7: Fiction

Bauer, Marion Dane.

An early winter.

New York, N.Y.: Bantam Doubleday Dell Books for Young Readers, 1999.

When 11-year-old Tim's beloved grandfather develops Alzheimer's disease, Tim tries to restore and save him by taking him out for a fishing adventure at the pond, but the outing turns into a disaster.

Mackall, Dandi Daley.

Horse whisperer I call Grandpa.

St. Louis, Mo.: Concordia Publishing House, 2000.

After she discovers what her grandfather had been collecting in jars that appear to be empty, Scoop understands that although her grandfather has Alzheimer's, he remembers the past.

Park, Barbara.

The graduation of Jake Moon.

New York, N.Y.: Athenaeum Books for Young Readers, 2000.

Fourteen-year-old Jake recalls how he has spent the last four years of his life watching his grandfather descend slowly but surely into the horrors of Alzheimer's disease.

Swallow, Pamela Curtis.

It only looks easy.

Brookfield, Conn.: Mill Brook Press, 2003.

Kat Randall's dog, Cheddar, is hit by a car driven by an elderly woman with Alzheimer's disease, Mrs. Lawrence. While Cheddar recovers, Kat and Mr. & Mrs. Lawrence become friends.

Grades 4-7: Nonfiction

Altman, Linda Jacobs.

Alzheimer's disease.

San Diego, Calif.: Lucent Books, 2000.

This book gives an overview of the disease, research, diagnosis and treatment. Includes a glossary and a section for further reading.

Willett, Edward.

Alzheimer's disease.

Berkley Heights, N.J.: Enslow Publishers, Inc., 2002.

Personal stories add interest to this overview. After a profile of the disease and a brief history, symptoms and diagnosis are described and treatment and social implications, studies about preventative measures and ongoing research are discussed.

Web sites

Brain: The world inside your head

<http://www.pfizer.com/brain/>

This web site was created and is maintained by Pfizer, a pharmaceutical company and distributor of an Alzheimer's drug. The site provides html and pdf versions of a teacher's guide and a family guide to explaining brain diseases. There is a virtual tour of how the brain develops, as well as other features.

Kidshealth for kids

<http://kidshealth.org/kid/>

(click on "Health problems of grown-ups")

Accurate, up-to-date and jargon-free health information kids can use. Has separate areas for kids, teens and parents, each with its own design, age-appropriate content and tone.

Neuroscience for kids

<http://faculty.washington.edu/chudler/neurok.html>

This meta site provides links to resources for teaching about neuroscience, as well as print resources, experiments, demonstrations, activities and worksheets.

Web topics - brain

<http://www.franceandassociates.net/wtbrain.html>

Includes a collection of web site reviews, centered on a theme. Included are lists of books, CD-ROMs, videos and other materials to help in forming a study unit or for branching off to related areas.

Videos

Poppy's head.

Angell Productions, videocassette (23 minutes), available from Angell Productions, 130 Brooklyn Road, Brooklyn, NSW, 2083, Australia. (02) 9985-7207; fax: (61) (02) 9985-7175. <http://www.angellpro.com.au/poppy.htm>

Teenager Zeb, the only child of a single, working mother, relies on Poppy, his grandfather, for company and guidance. When Poppy is diagnosed with Alzheimer's disease, Zeb's life changes drastically. He is forced to cope with Poppy's confusion and memory loss, while keeping a constant eye out for Poppy's safety and well being. Zeb also faces bullying and teasing from his classmates about Poppy's strange behavior. In the end, Zeb learns to cope with Poppy's illness and to take advantage of the time they still have together.

Head and Heart: A Lesson Plan

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The "Becoming Friends: Elders Volunteering in the Classroom" program integrates into the teacher's curriculum and meets the science, health and language arts academic standards required by the state.

Lesson One:

The difference between a child and an elder.

Kids learn about the myths of aging and the differences between themselves and elders. They discover there are more similarities than differences.

Lesson Two:

What is Alzheimer's?

The disease is explained in terms that a 10-year-old can understand. A discussion follows about why some elders develop it and why some don't. Kids also learn about the everyday struggles with the disease, such as coping with memory loss and behavior changes.

Lesson Three:

What do we do now?

To help the elders feel secure and be successful during their volunteer experience, the kids and the teacher brainstorm activities to do with them. They talk about the elders' needs, how to enjoy silly moments (but never laugh at the them) and how to communicate. An agenda is developed for each visit that meets both the teacher's learning objectives and that matches the elders' abilities.



Go to www.alz.org
to visit our kids and teens
information center.

Creating a Circle of Life — and Hope

Northwest High School students who participated in the Northeast Georgia program this year are (left to right): Justin Cole, Meghan Putnam, Sarah Hampton, Tasia Byers and Brett Cash.



Teenagers start by helping young children understand Alzheimer's disease. Then those children raise funds to support Alzheimer's research. It's a circle of life that helps each person touched by a program that offers hope for those who live with Alzheimer's every day.

For the past six years, Shara Cook, serving learner instructor for Northwest High School in Whitfield County, Ga., has worked with the Alzheimer's Association Georgia Chapter to bring awareness and understanding about Alzheimer's disease to local youth.

Her High School Serving Learner students volunteer to read the story "Grandpa Doesn't Know It's Me" to hundreds of elementary students and are trained to answer the questions that inevitably arise after such a reading.

This year, the students attended three in-service classes conducted by Laurie Parker of the chapter office. Armed with this training, the students worked with fourth- and fifth-grade classrooms in three local elementary schools.

The children were invited to bring in their "Nickels for Memory" to help fund research to help the families that deal with Alzheimer's.

A letter explaining the program to parents and soliciting their help went to each child's home. A contest was set up in each school, and the class raising the most money was rewarded with a pizza party (all donated funds are directed to the Alzheimer's Association). Last year, the program raised more than \$500.

From Toddler to Teen: Youth Volunteers for Alzheimer's

For the past 12 years, since the age of three, Liz Diamandis of Arlington, Mass., has helped herself, her family and her community understand Alzheimer's disease. And, in doing so, she has helped raise funds for the Alzheimer's Association, as well.

Since she was a baby, Liz has lived with Alzheimer's. Her grandfather (her father's father) and her great-grandfather (on her mother's side) both had Alzheimer's. When she was just 2½ years old, her grandfather, who lived with the family, died.

"I remember I helped care for him," said Liz. "I would play with him and share toys."

Motivated by her family, three-year-old Liz volunteered to help during the local Memory Walk sponsored by the Cambridge, Mass., chapter. At first, she helped with set-up. "My mom [Lisa Diamandis] and grandmother [Liz MacAskill] were volunteers. It simply seemed like the right thing for me to do." She has now participated in 10 Walks. This fall will mark her 11th Memory Walk.

Liz's other volunteer work has blossomed, as well. She has assisted at other Alzheimer's disease fundraisers, volunteers at the local chapter office during school vacations, and she has persuaded the town to donate booth space at an annual festival, to raise money and to distribute information on Alzheimer's disease.

Now 15, Liz continues to increase awareness of Alzheimer's among her friends and classmates. "My younger sister, Victoria, also volunteers," said Liz. "And I've gotten my friends interested, too."

Dallas Chapter Programs Help Youth Understand, Interact

With its Youth Alzheimer’s Awareness Programs, the Greater Dallas Chapter is helping youth groups provide information and education about Alzheimer’s disease and related dementia to guide kids as they encounter people with dementia and to enrich their service experience.

“Our programs are available for children of any age in schools, scouting organizations, vacation Bible schools and other youth programs,” said Kathleen Byrnes, Ph.D., Greater Dallas Chapter director of services and education and a licensed counselor. “Church youth groups, for example, may plan nursing home visits. We’ll present our program to prepare the children for what they can expect from a person with dementia and how they

can make their visits more meaningful and effective.”

For several years, the Greater Dallas Chapter has sponsored a badge program with area Girl Scouts, providing content and materials to help girls earn Alzheimer’s Awareness badges. When the chapter received increasing requests about similar education programs, it adapted the material for other audiences and age groups. The result is the Youth Alzheimer’s Awareness Programs, launched in spring of 2003.

The programs include education about Alzheimer’s disease, the stages of progression and how to communicate with Alzheimer’s patients. Depending on the age of the participants and time available, the modular programs can be

expanded to include a video to illustrate behaviors associated with dementia, interactive learning activities and role-play. The programs are led by Dr. Byrnes or by Lynda Taylor, volunteer and outreach coordinator of the chapter.

For More Information

About the Greater Dallas Chapter Youth Alzheimer’s Awareness Programs, contact Dr. Byrnes at 214.540.2412.



National Alzheimer’s Disease Month

This year marks the 20th anniversary of National Alzheimer’s Disease Month, which is commemorated in November each year.

Today, there are 4.5 million Americans diagnosed with Alzheimer’s disease. By 2011, 76 million baby boomers will begin reaching the age of greatest risk, and the number of people diagnosed with Alzheimer’s disease is expected to surge.

When former President Ronald Reagan announced to the American public in 1994 that he had Alzheimer’s disease, his openness helped build public awareness, lift the stigma of the disease and show families who are living with Alzheimer’s that they are not alone. The Reagan family has been one of the Association’s most effective partners in the fight against Alzheimer’s disease through national public service campaigns

and in advocating for more federal funding of Alzheimer’s research.

Since 1994, federal funding for Alzheimer’s research has more than doubled from about \$298 million to over \$600 million in 2003.

Memory Walk Makes a Difference

Memory Walk can take on as many different meanings and messages as there are walkers. Some participants walk alone or quietly with a single companion to commemorate a loved one. Corporate, church and fraternal teams march shoulder to shoulder. Observers also will see contingents of family and friends, like Peggy's Parade (see photo), 34 supporters who walked in the Chicago event last fall, decked out in special t-shirts and carrying a huge banner in honor of Peggy Kluck, who died of the disease just weeks after the 2002 Walk.

Memory Walk is the Alzheimer's Association's national event to support the Association's mission. Since 1989, Memory Walks, which take place primarily in September and October in more than 500 communities across the country, have raised more than \$120 million. Walkers ask friends, family, business associates and others to sponsor them by making a donation to the Alzheimer's Association. Funds raised are employed locally to maintain services, support groups and education programs.

Special thanks to our 2003 Memory Walk sponsors: GE Financial Advisors and Creative Memories.



**To find the date and location
of your local Memory Walk and
to register:**

www.alz.org/memorywalk

800.272.3900

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