



Perspectives

A Newsletter for Individuals with Alzheimer's or a Related Disorder

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Coping with Alzheimer's Attitudes and Ideas

At different times throughout life, everyone has to face a variety of challenging circumstances. Examples include the first day of school, picking a career, the birth of a child, managing a home, or retirement. All of these events require different coping strategies to deal with or manage the situation. Coping can be in the form of an attitude or an action, and methods vary from person to person.

With the onset of Alzheimer's there are many new things to cope with. Symptoms of memory loss can require finding new strategies for managing daily life. Relationships go through changes or adjustments, and some activities or responsibilities may need re-evaluating. Throughout this process each person uses coping strategies. Some of them may be old well-known methods, while others may be newer or less familiar.

Some people cope by developing a positive attitude. An attitude is an opinion or approach to something. One man says, "*I take it one day at a time.*" This approach to life makes things feel less overwhelming and more manageable. It allows him to focus on the present instead of worrying about the future. With his onset of Alzheimer's, Thaddeus Raushi writes about adopting a survivor's attitude by focusing on his strengths instead of his symptoms. He states, "*I continue to take*

advantage of my capabilities to build on what I can do and not simply bemoan what I can't do." He writes that although he does allow himself time to grieve his losses, he doesn't dwell on them. Rather, he uses his energy to make use of his many remaining abilities.

Many people with Alzheimer's also discuss the importance of humor as a coping strategy. Laughter can relieve stress and brighten a dark moment. One woman says, "*Laugh at yourself! We do funny things sometimes!*" Laughter also starts a chain reaction in the body that releases endorphins into the brain. Endorphins can help to create a sense of well-being and calm.

Do you have helpful attitudes or approaches that you use to cope with Alzheimer's? It might be helpful to write them down and remind yourself of them during difficult times. It is also important to look at any negative attitudes that interfere

with your coping. Everyone has down spells or times when it is hard to cope, but your attitude can make a big difference in how you get through the tough times.

Another way of coping is through making adjustments to our behavior. This includes evaluating our activities and developing creative strategies for managing memory loss. Many people find that staying busy is a helpful way of coping. Activity can provide meaningful and enjoyable distraction and take one's mind

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Coping with Alzheimer's

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off of symptoms. One woman says, *"I don't think about Alzheimer's! I have lots of other wonderful things to think about - children, grandchildren, reading, walking, eating, and chocolate!"* Another man agrees with this approach and says, *"When my mind is on something else, I can't think of myself, so I stay busy."* Some people feel that they have plenty of meaningful activity while others struggle to find ways to fill the time. Symptoms may interfere with doing previously enjoyed hobbies, and it is important to come up with new ways to stay involved in life.

Another method of coping is through seeking and giving support. People with Alzheimer's support one another through participating in groups, social programs, email chat rooms, or other activities. The camaraderie of being with others who understand can ease feelings of isolation or stigma. One man talks about his support group, *"It's my salvation to be able to go to a place and be around others in the same predicament. We can get out of the predicament for a while by being with a group of friends."*

Symptoms of Alzheimer's can be frustrating and some people need to *"let off steam."* It is important to acknowledge the challenges. One man says, *"I cuss a lot inwardly - it takes the edge off. I don't cuss outwardly unless someone steps on my toe!"* Some people find that physical exercise is an important coping method that releases tension. Some enjoy the company of a pet on a walk. Another man says, *"My little dog takes the edge off. He doesn't talk back or tell you you're crazy."*

Finally, many persons with Alzheimer's develop creative and practical methods of coping with symptoms such as making

lists, using calendars, or getting medication organizers. Others discuss strategies to stay organized like always keeping certain things in the same place, simplifying wardrobe decisions, or labeling cabinets and drawers. Some get a Safe Return bracelet through the Alzheimer's Association or another form of medical identification to help them in an emergency. All of these behaviors are positive coping methods for managing daily living.

What actions have you taken that have helped you to cope? Have you changed your behavior or done something new as a result of Alzheimer's that has been helpful? Have any behaviors or actions limited your ability to cope? Coping strategies are acquired and used throughout life. You may rely on ones that have worked for you over the years, or you may find that Alzheimer's is a new experience that requires new skills. It's never too late to develop helpful coping strategies. Find out what ones work for you and share them with others!

Editor's note: All quotes came from back issues of Perspectives or are from the Editor's conversations with people with Alzheimer's.

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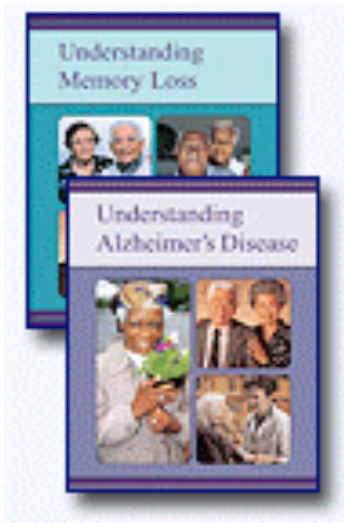
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Helpful New Resources



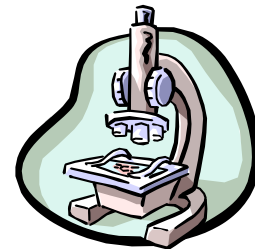
Alzheimer's Disease Education and Referral (ADEAR) has published two new brief, easy-to-read publications on Alzheimer's disease and memory loss. "Understanding Alzheimer's Disease" is a 12-page booklet that provides basic information about signs and symptoms of Alzheimer's and addresses medical care and participation in clinical trials. "Understanding Memory Loss" is a 16-page booklet that discusses the differences between normal and abnormal memory loss, causes of memory loss, ways to help your memory, and how to get a medical evaluation. Both booklets are written in large print, in plain, straightforward text.

The publications are now available online in a PDF format that you can print out at <http://www.nia.nih.gov/Alzheimers/Publications/UnderstandingAD> and

<http://www.nia.nih.gov?alzheimers/Publications/UnderstandingMemoryLoss>.

You can also get a copy by mail by calling ADEAR at 1-800-438-4380. ADEAR is a service of the National Institute on Aging and provides a great deal of valuable information about Alzheimer's disease and related dementias.

RESEARCH UPDATE



Genetics Study

Many people with Alzheimer's wonder if it is inherited or if they will pass it on to their children. Although there are some genes identified for those who get Alzheimer's at a young age, these genes account for fewer than 5% of all cases of Alzheimer's. Some forms of a gene (called ApoE) can put older people at greater risk of getting the disease, but scientists think there are probably more genes that can influence who will develop symptoms. Understanding genetics can pave the way for better treatments, prevention, or a cure.

The National Institute on Aging, the National Alzheimer's Association, and study sites across the United States are working together to conduct the Alzheimer's Disease Genetics Study and are looking for volunteers. They need families with at least three members who can donate blood and participate in an interview. Necessary family members include:

- ❖ Two siblings (brothers or sisters) who developed Alzheimer's after age 60 and
- ❖ Another family member over 50 who may have memory loss or a family member over 60 who does not have any memory loss.

Family members do not need to live near one another to participate. If you would like more information about this important study, call 1-800-526-2839.

Together: Sharing the Experiences of an Early-Stage Support Group

By
Dayna Morrow and Participants of the
Early-Stage Support Group in
Montreal, Quebec, Canada

To ask just one of the twelve members of the early-stage support group to share their experiences regarding their participation as a group member seemed unjust as all of these spokespeople have something valuable to contribute to the discussion. As such, below they will share with you their accounts as members of this vibrant and energetic group.

Their ages range from their early 60's to mid-80's and there is a wonderful mix of religions and cultures to add to the spice and chemistry of the group. Some members have been together now for more than two years with new faces joining them on a regular basis. I sat down with the group to discuss their experience within the support group environment and to ask them to serve as mentors by encouraging others living with the diagnosis to break the isolation and reach out, as they did, for help in their daily living environment. Below is the account that the group members provided regarding their experiences within the support group:

Dayna: Tell me what brought you to participate in a support group for people diagnosed in the early stages of Alzheimer's?



Group Members: Many of us were reluctant at first. It was scary to find that we had Alzheimer's. Who would understand us? What would it mean to live with this diagnosis? For many of us, we were depressed and isolated with this diagnosis, but wanted to know more about what was ahead for us. Several of us had our kids or spouses initially make the call to the Alzheimer Society of Montreal; however some of us called ourselves, and we're so happy we did. Everything has been so much better since we've come here.

Dayna: When you say better, what does that mean?

Group Members: It means not being as alone. It means knowing that we're not crazy, that there are other people living exactly the same thing as we are. We love to come here because we talk and have fun and here, there are no worries, no judgments. We've all learned so much about the disease, too. Even though we sometimes forget the details, we can always come back and ask for more information later. Some of us have kids or spouses in the group happening at the same time in the next room, so this helps them to learn about us...and hopefully helps all of us know what to do next.

Dayna: So what would you say have been the benefits of the support group for you?

Group members: Definitely talking with others who don't judge us. Here it never matters if we forget or make a mistake. We're all the same here and Dayna makes us laugh and have fun. She organizes "brain exercise activities" to keep us thinking and working the old noggins! We

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Early-Stage Support Group

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like to just be together though, and we wish we could meet even more often! It also helped many of us discuss Alzheimer's more openly with family and friends and we've learned about research, medication, and now we have a little more hope. Some of us have learned a few new tricks, too, like keeping a regular agenda, jotting down notes, and making other changes to help us remember things. It doesn't always work, but it helps to know there are some options.

Dayna: What would you tell other people in the early stage who might be considering joining a support group but are hesitant to call?

Group Members: We'd tell them just do it – there is nothing to lose and a lot of help here for them. Plus, they'd get to meet us and we're a fun bunch! We'd also tell them to do it for themselves, that there is hope out there, and that talking with other people who are living this really makes a difference in the world. We'd also tell them we know how they feel, we've been there.

Perspectives Editor's note: This article is reprinted with kind permission from the newsletter of the Alzheimer' Society of Montreal, Spring, 2006, Volume 24, No 1.

There are early-stage support groups across Canada, the United States, Europe, Australia, and other regions of the world. If you would like to join a support group, contact the Alzheimer's organization closest to you for more information. If there is no group in your region, ask that one be started!



Oh How Can I Tell You

By Peter Beeson

*Oh how can I tell you
What this is like
How it is to be this way?*

*To be partly here
To know some things
And not others.*

*To be sort of present
But not really
To know this but not that.*

*Oh how can I tell you
That I can't remember
Our wedding date?*

*I remember the wedding
The trip to Valentine
Just not when.*

*I'm so sorry
I feel so bad
I don't want to make you sad.*

*It's not that it's not important
It's not that I don't care
It's not that we're not special.*

*It's not what I would choose
It's not what I want
It's just the way it is.*

*It's not that I don't care
It's not that I don't love you
It's just the way I've become.*

*I ask that you forgive me
Over and over again
That you remember where we've been.*

*I'm so glad that we're together
So grateful for us
So thankful for you.*

*I'm so sorry I don't know
I do love you so
I just wanted you to know.*

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The Driving Controversy: Alzheimer's and the Automobile

Editor's note – This article was originally published in Perspectives over 10 years ago. It continues to be such an important topic to readers that I have updated and revised the article for this issue.

To drive or not to drive. This is a big question common to many people with Alzheimer's or a related disorder. While we can't make that decision for you, we can answer some frequently asked questions on this issue:

How can Alzheimer's affect my driving?

Symptoms of memory loss, disorientation, and changes in vision and perception may result in drivers getting lost, misjudging distances, forgetting the "rules of the road", or having slowed reaction times when making the many quick decisions needed to drive safely. Concentration can be affected as well as coordination. Some people with memory loss are more easily frustrated in stressful situations. This can affect driving performance.

Will my license be taken away because of my diagnosis?

It is unlikely that you will have your license automatically taken away due to a diagnosis of Alzheimer's or a related disorder. In some regions of the United States, physicians are required by law to report a diagnosis of Alzheimer's to the Health Department who then reports to the Department of Motor Vehicles (DMV). Sometimes concerned family or friends make a report. The DMV then asks you to come in for a written and driving test. Some people with mild symptoms pass the tests and can continue driving. Many oth-

ers do not and must stop driving. These reporting and testing procedures vary greatly from state to state. Check with your local DMV for regional specifics.

Many people with Alzheimer's have clean driving records and resent that others are telling them to stop driving. It is wiser to quit driving while you can still take pride in your driving record than wait until you have an accident in which you hurt yourself or others.

Do people with Alzheimer's get in more accidents?

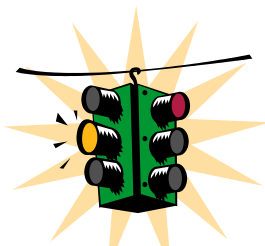
Studies indicate that drivers with Alzheimer's are more likely to get into car accidents. Some findings suggest the accidents are more often "fender benders" than major collisions, but there have been tragic cases of people with Alzheimer's causing loss of life in serious accidents that were due to their symptoms.

How can I know if I am an unsafe driver?

You may not be the best judge of your driving. Sometimes a friend or family member notices problems first. Look for the following signs or try to listen if someone points them out to you. Although everyone makes mistakes, repeated errors are cause for concern:

- Forgetting how to get to familiar places due to memory loss.
- Misjudging distances due to changes in vision and perception.
- Not following traffic signals including running a red light or stopping at a green.
- Poor decisions in traffic, including not using turn signals, weaving across lanes, becoming confused in four-way intersections, or not yielding to traffic when necessary.

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The Driving Controversy

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- Driving too slowly or too quickly.
- Losing your temper more quickly or becoming more easily frustrated.

Talk with your doctor or other health care professional to review your symptoms and their possible impact on your driving.

If I drive with a license and get in an accident, can I be sued?

If you have a driver's license, you have the legal right to drive. However, if your disease progresses in ways that affect your driving safety you should stop before it's too late. If you get in an accident, someone could charge that you knowingly drove (or your family let you drive) in a disabled condition that put you and others at risk. This could result in a lawsuit.

If I stop driving, how will I cope?

For many, driving is a symbol of independence and freedom and it is very hard to give up the keys to the car. Others voluntarily give up driving and are relieved to let someone else assume the responsibility. Sometimes it is difficult not to take the whole issue of driving personally. Remember that Alzheimer's is only one of many medical conditions that put a person at risk for unsafe driving. You are not being singled out and you are not alone.

Explore other means of transportation. Walking can be pleasurable for shorter distances, or friends and family are often willing to provide transportation. Some people are able to use public transportation services or other community transportation services. It is important to focus on your remaining choices and abilities. Whether you are behind the wheel or not, you can still have some say in both the journey and the destination.

Alzheimer's Web Site Wins Award



In this newsletter's article on coping, we discuss the ways that people with Alzheimer's can provide one another with support and camaraderie. The growing popularity of computers has created the opportunity for internet communication between people all around the world. Although some find it difficult to use a computer, others acquired this skill prior to the onset of Alzheimer's and retain the ability for some time. Others seek help from a friend or family member, so they can access the resources and support that is available online.

A group of people with dementia from the West Kent branch of The Alzheimer's Society in the United Kingdom (UK) are making good use of their computers. They recently won an Innovation in the Community Award from America Online (AOL), UK for their website, "The Alzheimer's Forum." The web site is at <http://www.alzheimersforum.org> and is run by and for people with dementia as a means of sharing coping ideas, experiences, and support. Questions are posted by people with Alzheimer's or a related disorder and others can answer and share their ideas. The web site has connected people from around the world and the creators of the Alzheimer's Forum encourage others to participate.

Congratulation to the creators and participants of the Alzheimer's Forum for this well-deserved award!

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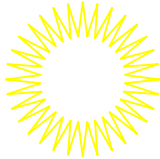
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