

# Alzheimer Society

SAULT STE. MARIE &  
ALGOMA DISTRICT

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## EXECUTIVE REPORT



Once again we are approaching the Christmas season, and the board and staff of the Alzheimer Society would like to wish you an enjoyable holiday. Although requests for our services usually decrease somewhat over the Christmas season, we know that this can be a particularly stressful time for families experiencing health issues. We remind you that the Alzheimer Society is here to help and is able to provide information, support, and referrals that might make the journey a little easier.

The Society has had a busy fall. September was a particularly busy month with two of our major fundraisers, Coffee Break™ and the Algoma Fall Craft Show, as well as the provincial election campaign, happening in this month. We, along with other local Chapters, contacted candidates to ensure that they were aware of the issues facing people affected by Alzheimer Disease.

Our local Dementia Network, ever conscious of the need to inform people about the services available for people affected by dementia, is wrapping up the Care Map project. Posters for health professionals in North and East Algoma will be distributed by Christmas. The Network has also made the decision to go forward with the development of a web site. Stay tuned for more information as we get closer to a "go live" date.

Merry Christmas to all!

Carolyn Cybulski  
Executive Director

Paul Hebert  
President

## MARK YOUR CALENDARS!

The 2004 Alzheimer Society  
Education Conference  
will be held on Monday, March 29, 2004  
8:30 a.m. - 4:30 p.m.  
at the Best Western Great Northern.

The morning will feature various presentations on topics relevant to caring for people with Alzheimer Disease (agenda in development).

The afternoon session will be dedicated to Jayne Harvey's interactive session on the topic of sexuality and dementia. You may remember Jayne from the "Strawberries for Breakfast" presentation she did at our 2002 conference. We received extremely positive feedback from that session and decided to bring her back for this very relevant and sensitive topic.

Brochures will be sent out in January. Please contact our office at 942-2195 to ensure your name is on the brochure mailing list.

Our mission: To improve the quality of life for people with Alzheimer Disease and related dementias, and to provide support for their caregivers.



Office hours are Monday to Friday  
8:30 a.m. - 4:30 p.m.  
Evenings by appointment.

❁ January is Alzheimer Awareness Month. The following activities are planned as we take this opportunity to step up our awareness and fundraising efforts:

- ▶ Proclamation of January as Alzheimer Awareness Month at various Algoma municipalities.
- ▶ Educational displays at various times throughout the month of January at: Cambrian Mall, Station Mall, Sault Ste. Marie Public Library, and the Civic Centre.
- ▶ Alzheimer Society Open House on Monday and Tuesday, January 5 and 6, 2004 from 8:30 a.m. to 7:00 p.m. Meet our staff, take a tour of our office, review our educational information, and enjoy some refreshments. Everyone is welcome.
- ▶ Please see Bea Fioramanti's column for information about the Walk/Run for Memories and the Door-to-Door Campaign, both occurring as part of January Awareness Month.

❁ Have you completed one of our surveys? The Alzheimer Society is undertaking a Needs Assessment over the next few months to determine which services are important to you and what method of delivery would be most helpful to you. If you have not completed one and would like to, please contact our office.

❁ Many thanks to 87-year old Cliff Farnsworth for knitting up a big batch of dishcloths, and to the staff of ASCU who purchased them and donated the proceeds to the Alzheimer Society. Your gifts of time and money are greatly appreciated.

❁ Thank you to the Knights of Columbus #11608 for inviting the Alzheimer Society to partner with them on their first annual Wild Game Dinner. Over 100 people enjoyed a wild game feast, music, dancing, and a door prize. It was a very enjoyable evening and we thank all who participated.

❁ Safely Home at Last! People with Alzheimer

Disease sometimes lose the ability to recognize familiar places or to remember their names and addresses. They may leave home, become confused, and get lost. But there is help. Safely Home™ is a nationwide program designed to help find a person with Alzheimer Disease and assist in a safe return home. Developed by the Alzheimer Society of Canada in partnership with the RCMP, the registry stores vital information confidentially on a police database that can be accessed by police anywhere in Canada and the US.

Here's how it works: If a loved one goes missing, the caregiver calls the local police. Accessing the computer database, information about the registrant is matched using personal information. A registrant is found when the police are able to use the information number on the identity bracelet worn by the person with Alzheimer Disease to search the database. Registration is voluntary and simple to do. For a one-time fee of \$25, the registrant will receive an identification bracelet and cards. Wearing the bracelet and carrying the cards in places such as wallets and coat pockets aids in quickly identifying people should they become lost. To register with Safely Home™, contact the Alzheimer Society office.

Board of Directors 2003-2004

Paul Hebert, Jr., President	Shelley McEachern
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Vicky Roy, Family Support Case Worker
Monica Ruzyski, Bookkeeper
Linda Sullivan, Education Coordinator
Bea Fioramanti, Events Coordinator
Kara Benka, Recreation Therapist

Excerpt from a letter from one of our community partners...

I am writing this letter because of the effort that is made by Heather Hamilton each year on behalf of the Alzheimer Society. Heather is an Occupational Therapist with the Algoma Community Care Access Centre...I was overwhelmed with the amount of work that she put into preparing for the Alzheimer Coffee Break. We have a large staff room and it was filled with baking of all kinds, gluten-free products, fruit, juice, and coffee...For those that donated over a certain amount, they wrote their names for a draw that would occur later in the day for baking, hand made items and forget-me-not stationary and pins. As well, the remaining baking was packaged up and sold for \$2.00 a plate...I wanted to ensure that Heather is somehow recognized for her quiet commitment to your organization.

Sincerely, Mary Tasz, Manager of Therapy Services

Editor's Note: The Algoma Community Care Access Centre, led by Heather Hamilton, was successful in raising \$602 in Coffee Break 2003 and was the winner of the Golden Coffee Cup Award for the Community Agencies sector. The Access Centre has raised close to \$1,700 in the years it has been participating in Coffee Break. We are very grateful to the commitment of the Access Centre and the many other businesses, organizations, and individuals who support



Jerry Demers from Agawa Indian Crafts accepts one of the 11 Golden Coffee Cup awards from Bea Fioramanti for raising \$526.72 in Coffee Break 2003.

## Have you made plans for your Staff Christmas Party?

Best Western Great Northern is offering a Christmas Luncheon Celebration on Friday, December 19 from 11:30 a.m. to 2:00 p.m. There will be a full buffet featuring snow crab and succulent carved roast beef, as well as live entertainment, a visit by Santa, and door prizes including travel and spa packages. Tickets are \$25 and are available from the Alzheimer Society or the Best Western. A portion of the proceeds will be donated to the Alzheimer Society.

Do you have family or friends coming at Christmas?

The Best Western is also once again offering its Friends in Need program. From December 18 - 26, the hotel will be offering its rooms at the discounted rate of \$32 to facilitate the coming together of friends and family over the holiday season. \$12 from the sale of each room will be donated to the Alzheimer Society's Recreation Therapy program. For reservations call 1-800-563-7262 or 942-2500.

Thank You

to our Nevada Ticket locations:

Northgate Service Centre at Montreal River Harbour, and I DA Drug Mart at Station Mall.

Please support these community-minded businesses.

Thanks to summer student Tara Donaghue for her valuable assistance in Coffee Break™ 2003. ☺

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*This newsletter is based on the assumption that it does not render professional advice. Information and opinions contained herein are gathered from sources thought to be reliable, but their accuracy and/or correct interpretation cannot be guaranteed.*

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## Coffee Break...

A BIG thank you to all of our Coffee Break™ supporters for the overwhelming success in raising funds and awareness for Alzheimer Disease. This year's event raised over \$19,000 - a record! The Coffee Break™ kick-off at Rome's Independent Grocer was the place to be, with visits from local celebrities who helped serve up "a cup for a cure".

Collegiate Heights' generous donation of their dining room and all refreshments contributed to the great success of our first Forget-Me-Not Tea. Patrons of this event enjoyed their tea and dessert in the warm atmosphere of this elegant building.

We would like to extend special thanks to the many dedicated volunteers whose help is greatly appreciated, and to our sponsors: Sault Star, KPMG, Penny's Pets, Travelmasters, and the Co-operators on Northern Ave.

The Dessert and Coffee Deal grew this year, with more restaurants offering their tasty desserts and coffee and donating a portion of the sale to the Alzheimer Society. Big thanks go to Giovanni's, Joey Calzone's, Thymely Manner, U-Betcha, Vincenzo's, and the Wawa Motor Inn.

Our Coffee Break™ decals adorned the windows and walls of these community-minded businesses: Food Basics (Pine St. and Trunk Rd.), Absolutely Delicious, Taste of Scandia, East St. Coffee Shop, Dinelle's Country Market, and Canadian Tire in both Sault Ste. Marie and Elliot Lake. Much appreciation goes out to these businesses for agreeing to sell our coffee cup decals, and to the patrons for their willingness to "sign a cup and donate a buck".

The Alzheimer Society wishes to recognize the generous assistance of Pfizer Canada Inc. and Barthelmes Art Studio in the creation of the Golden Coffee Cup Award which was presented to the organizations raising the most money in each of

the 11 categories. Congratulations to the winners:

Care Facilities	Sault Area Hospital
Elementary School	Isabel Fletcher
Secondary School	CASS
Post Secondary Education	Sault College
Home Parties	Carol Thomas
Industrial/Construction	St. Mary's Paper
Retail/Commercial	Agawa Indian Crafts
Financial/Insurance	ASCU Bay St.
Churches/Associations	Community of Christ
Government Offices	Great Lakes Forestry
Community Agencies	Algoma CCAC

## Algoma Fall Craft Show...

We would like to extend our thanks to organizers Gerlinda Haeffele and Lucy Boston who work so hard every year to make this event a success, and to all the artisans who donated their hand-crafted treasures to our Silent Auction Table. This popular event has become a fall tradition!

## Upcoming Events...

Walk/Run for Memories...Refreshments, prizes, entertainment, and lots of fun await you at this fun-filled family event at the George Leach Centre on Sunday, January 18. Children will enjoy having their faces painted, visiting with the clown, and receiving their very own piece of balloon art! Teams are welcome to challenge other teams for the title of highest team pledge earner. Call 942-2195 for more information and to find out how to get your registration/pledge form.

Door-to-Door Campaign...January is just around the corner, and as a new year starts, so too does the Alzheimer Society's annual Door-to-Door campaign. Please be generous when a canvasser calls. If you are interested in canvassing a street in your neighbourhood, please call Bea at 942-2195.

On behalf of the Alzheimer Society Board of Directors and Staff, I would like to "WELCOME" all of our new volunteers. We are happy to have you on board and hope you will enjoy the job that you have volunteered for. I look forward to working with you in the future. If you have any questions or concerns, please don't hesitate to call me at 942-2195.



Thank you to all of our volunteers who, since our last newsletter, helped with Information Booths, office work, Algoma Fall Craft Show, Tea & Dessert, and Annual Coffee Break. And to those who visit clients on a regular basis, you really make their day!

VOLUNTEER OPPORTUNITIES: There are always opportunities for those wishing to volunteer a few hours of their time:

**DOOR TO DOOR CANVASSING:** Come out and walk off that turkey, potatoes with gravy and all of that Christmas baking! Visit your neighbours you haven't spoken to in awhile! We need canvassers for our 2004 campaign. Canvass five, fifteen or fifty homes - it all helps!

**WALK FOR MEMORIES:** Once again come out get your walk in at the George Leach Centre on Sunday January 18, 2004. Bring your friends and family for a day of fun and get your exercise too! You can pick up your pledge sheet at the office or give us a call and we will get it to you. If you would like to help out behind the scenes that day give me a call at the office.

**BINGO:** We are always looking for volunteers for our Tuesday evening bingo. If you are interested in being part of a team, sparing on a team, or if you have 5 people available to make up a team, please give me a call.

UPDATING VOLUNTEER INFORMATION FORMS: According to the Society's volunteer policy, we require all of our volunteers to fill out a "Volunteer Information Form". We require basic personal information such as your interests, level of awareness of Alzheimer Disease, preference of volunteer activities and any previous volunteer experience. For new volunteers, we also require up to 3 references as some of our volunteers work directly with clients. The information we receive is strictly confidential and is not shared with any other organization. We also require all volunteers to sign a Confidentiality Form. We are currently in the process of updating our files. In January, all of the Door to Door Canvassers will receive an information form in their kits. We ask that you please fill it in and return it with your Door to Door kit. All other volunteers that have not filled out this form yet or if your file needs to be updated, you will be receiving one in the mail in the new year and we would ask that you fill it out and return it to the office. I thank you in advance for your assistance.



**Cuddle Bears...** Touch is one of the first sensations we respond to and one of the last we lose. It provides stimulation and has the potential to stir up memories that have long since faded. This is the rationale behind the Alzheimer Society's "Cuddle Bear" Program. Over the past year, volunteers have donated armfuls of cuddly hand-crafted bears. Each bear is unique with its own personality, charisma, and vibrant colour. During Alzheimer Awareness month we distribute the bears to nursing homes across Algoma District to bring a measure of comfort to those in distress. If you are interested in knitting, crocheting, or sewing a cuddle bear contact us at the Alzheimer Society. We have a good selection of donated yarn and would be happy to give you a few balls if you don't have any.

Creutzfeldt-Jakob Disease

This rare fatal form of dementia was first reported in the 1920s and is part of a collection of rare human and animal dementias known as transmissible spongiform encephalitis. It kills about one in every one million Americans annually.

Unlike Alzheimer Disease which progresses slowly (average 8-12 years), more than half of the people with Creutzfeldt-Jakob Disease (CJD) die within five months of onset. Early symptoms include failing memory, mood changes, and motor difficulties such as involuntary jerking and difficulties walking.

The combination of the extremely rapid rate of decline, involuntary jerking movements, and specific EEG test results allow for an accurate diagnosis of CJD. Abnormal proteins in the brain called prions are responsible for the progressive damage. A damaged prion bumps into a healthy prion and causes the healthy prion to take on the abnormal conformation. As the number of abnormal prions increases, the rate of progression increases. This explains the rapid rate of progression.

In humans, prion disorders occur in three forms: most cases are referred to as sporadic or random (no family history or known cause of infection); one in ten cases is genetic; and very rarely it is transmitted from an infected person through exposure to an infected brain, spinal cord tissues, or corneas during medical procedures or through eating infected meat. This was the case in England in the 1980s. Mad Cow Disease (bovine spongiform encephalopathy) is thought to have started by feeding cows infected sheep meat and bone meal, and then feeding calves recycled meat and bone meal from dead cows. Humans who ate the meat from these infected cows developed a new variant CJD. These practices have been banned and Mad Cow Disease has been brought under control.

Caregiving techniques and strategies have to be continually modified because of the speed of progression. Symptoms can be unpredictable and are different for each person. Some symptoms include personality changes, impaired speech and comprehension, insomnia, delusions, vivid hallucinations, blindness, physical injury due to loss of balance and seizures, incontinence, immobility, and rigidity.

There is no treatment to cure or control CJD. Care strategies focus on creating a quiet, restful environment. Medications and therapies are used to reduce pain and alleviate symptoms. Infection control procedures must be used during personal care and medical procedures to avoid contact with body fluids. Regular social contact does not present a risk.

It is important for the family members and caregivers to receive ongoing education and support. Understanding the disease process, symptoms, consequences, changes in family roles and responsibilities, and resources available will help them cope with the challenges ahead. Counseling can be extremely helpful for families as they often don't have time to grieve for their losses during the progression of the disease.

Much research progress has been made toward understanding the cause of CJD and finding ways to treat it. This information has also been beneficial for researchers in the area of Alzheimer Disease.

Source: Alzheimer's Care Guide, April 2003

Stay tuned for the next installment of The Dementia Puzzle Series in our Spring issue.

This article, written by Cindy Ellen Crawford, originally appeared in Senior Life (a Sault Star speciality publication) on November 21, 2003.

### Stimulating Memories

A way to bring joy and stimulate memories can be as easy as assembling a box of mementos.

Kara Benka, a recreation therapist with the Alzheimer Society of Sault Ste. Marie and Algoma, suggests assembling a memory box that everyone can enjoy. This is particularly important if a family member is suffering from dementia or memory loss.

"You want to collect things that are significant to that person's life," she says. Items can include photos, trinkets, something that represents what they did in their career or special keepsakes.

"A Life Box is a celebration of self," she explains. "It is a wonderful way for people to get back their identity and for family members to share in that experience."

Benka suggests a shoe box-sized container. She also suggests labelling the contents so that whoever is going through that box can understand the significance of each item or photo.

"It can become a legacy to an individual but it means so much more to share it when that person is alive."

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Editor's note: The Alzheimer Society's Recreation Therapy program is in full swing, with Kara already having provided service to over 20 individuals in the first four months of the program. Initial results are very favourable: people with dementia are enjoying Kara's visits and their caregivers are gratified to see loved ones engaging in favourite activities that they thought were lost to that person. The first phase of formal evaluation will be beginning soon. The Alzheimer Society would like to recognize the contribution of the Ontario Trillium Foundation, an agency of the Ministry of Tourism, Culture, and Recreation which receives annual \$100 million of government funding generated through Ontario's charity casino initiative.

### Helping Children Understand Alzheimer Disease

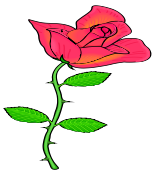
Children who have relatives with Alzheimer Disease may experience a variety of conflicting emotions. A child may feel:

- sad about the changes in the person's personality
- confused about how people get the disease
- afraid because the person may behave differently
- worried about self or parents getting the disease
- angry or frustrated by the person's need to repeat questions or activities
- guilty for getting angry with the person
- jealous and resentful because of the increased amount of time and attention that is given to the person
- embarrassed to have friends see the person with the disease.

It's important to talk with children openly about the disease and give them the opportunity to ask questions and express their concerns. Children should be encouraged to continue interacting with the person with Alzheimer Disease, and may find some of the following communication tips helpful:

- be kind to the person even when he repeats himself or can't remember something
- say your name each time you visit
- speak slowly and clearly
- turn off the radio and TV when talking to the person
- make eye contact when talking to the person
- don't argue with the person - he will not understand the reason
- don't get upset if the person seems angry
- break activities into small steps
- don't forget to hug (if the person likes hugs) - we all need to be loved.

By encouraging children to maintain and nurture their relationships with their relatives with Alzheimer Disease, we open up for them a world of rich experiences and an appreciation of the value of all persons. Remember to call the Alzheimer Society for more information. We can help you help your children.



### In Memoriam

We offer our sympathy to families in Algoma District who have lost loved ones (listed below), and we express our thanks to family members and friends who make donations in their memory.

New Additions to the Katherine L. Punch Resource Library

Gene Kucaba  
Helen Reid  
Len Montgomery  
Wallace McGuire  
Florence Belair  
Paul Rainone  
Dorothy Lewis  
Jenny McLelland  
Leopold Belair  
Ralph Quinette  
Lorna McCauley  
Rita Boniferno  
Hazel Moore  
Catherine Clouthier  
Frank DiGasparro  
Howard James  
Don Mei  
Neressa Cameron  
Walter Kolkoski  
Mary DiStasi  
Eva Chevrier  
Walter Kozak  
Ed Booth  
Frank DiGasparro

William Baic  
Patricia Watts  
Anton Stuetz  
William Macguigan  
Mr. Pandzie  
Hilda Hillman  
Beth Barker  
Allen Manchester  
Howard James  
Grace Case  
Grace Hanson  
Harvey Nivins  
Ernie Lavoie  
Mary Goddard  
Greg Pavalich  
Ephrom Gratton  
Fritz Koschwanez  
Laura Littleton  
Adrien Litalien  
Vera Thom  
Adeline Linklater  
Hugh McPhee  
A. Campbell

#### Videos

- Working Together: Developing a Relationship with Your Doctor. Alzheimer Society of Canada. 2003.
- Dementia With Dignity: A practical guide for carers of people with Alzheimer's Disease & other forms of dementia. Eastway Communication.

#### Books

- Don't Take My Grief Away From Me. Doug Manning. 2003.
- "The Gifts You Bring" Series: Your Gift of Participation; Your Gift of Peace; Your Gift of Presence. Doug Manning. 2003.
- Alzheimer's Early Stages: First Steps for Families, Friends, and Caregivers. Daniel Kuhn. 2003.

Please come in and visit our resource centre. We have hundreds of books and videos on a wide variety of dementia-related topics.

Interesting website: [www.lewybodyjournal.org](http://www.lewybodyjournal.org)



### SUPPORT THROUGH MEMBERSHIP

Please show your support for the work of the Alzheimer Society of Sault Ste. Marie and Algoma District. To become a member or make a donation, please complete, detach, and return to our office at: 633 Albert St. E., Sault Ste. Marie, ON P6A 2K5

G Membership:  Individual \$15.00  Seniors/Students \$10.00

G Donation: \$ \_\_\_\_\_

As a member you will receive:

1. Our newsletter published three times per year.
2. Notice of upcoming events and support group meetings.
3. Voting privileges at our annual general meeting.
4. A charitable tax receipt.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Thank you for your support!