

# Alzheimer's Disease and Related Dementias (ADRD) in Aboriginal Communities

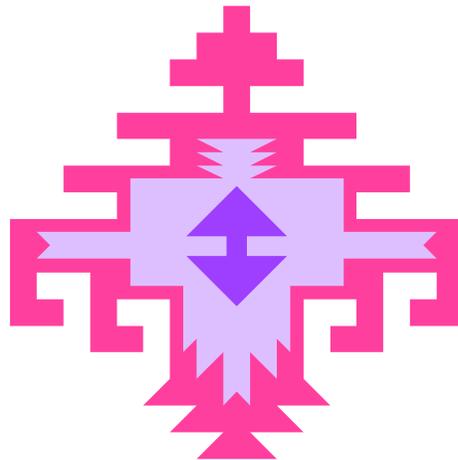
***“New Visions and Understanding”***

*Alzheimer's Disease and Related Dementias  
within Aboriginal individuals --  
Roundtable Forum  
March 21 – 22<sup>nd</sup>, 2007  
Sudbury, Ontario*



## *SPONSORS*

*Ministry of Health – Long Term Care -- Alzheimer Society Ontario  
Mnaamodzawin Health Services Inc. -- Noojmowin Teg Health Centre  
Northern Ontario School of Medicine*



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# Acknowledgement

New Visions – ALZHEIMER’S DISEASE AND RELATED DEMENTIAS (ADRD) within the rural and urban native population is based on the outcomes of a meeting that took place in Sudbury, Ontario on March 21<sup>st</sup> & 22<sup>nd</sup>, 2007.

By increasing awareness of the history of our Aboriginal people and the impacts of colonization, residential school abuse and the unique values and beliefs of Aboriginal People, it is hoped that this meeting will mobilize services providers, educators, researchers and Aboriginal people to work more closely together in support of a common strategy in dealing with Alzheimer’s Disease and related Dementia’s within the Aboriginal communities both rural and urban.

The Roundtable Forum represents a collaborative effort shared by many individuals highly committed to promoting cultural understanding and healing of Aboriginal people who experience issues with Alzheimer’s Diseases and related dementias.

Because of the unique position of Government Funders, Alzheimer Society Branches, First Nations, Aboriginal Organizations, and Traditional Healers all have an important role in the future development of Aboriginal educational resources and a comprehensive strategy in responding specifically to ADRD currently or in the future.

We gratefully acknowledge the contributions of forty participants that made up this important roundtable forum in Sudbury. Their willing participation in a two day forum identified key aspects of understanding the culture and traditional teachings for Aboriginal people throughout our land. The group identified a number of future action steps to enhance education, treatment and cultural understanding for providers, family and communities in general.

As well, we acknowledge and honour the Elder, Stella Corbiere from Wikwemikong whose cultural wisdom help guide us throughout this two day process.

Thank you also to the Ministry of Health and Long Term Care for the financial support of the two day forum would not have been possible.

Finally, a special acknowledgement to those individuals that are **living with ADRD** and their families, **caregivers** and communities who are providing ongoing service of inspiration and hope for the future.

# PREFACE

This Roundtable Forum was conducted through the partnership of the Alzheimer Society Ontario and Mnaamodzawin Health Services Inc. (Manitoulin Island) in collaboration with Noojmowin Teg Health Centre, Northern Ontario School of Medicine, Alzheimer Society of Sudbury-Manitoulin and the Ministry of Health and Long Term Care-Aboriginal Health Unit.

This project could not have been accomplished without the support and cooperation of the above mentioned organizations committing to multiple meetings for a number of months to develop a clear set of goals for the two day forum.

Administrative assistance for this very important project was provided by Jacquie Butler and Beverly Nahwegahbow, Chi Miigwetch for helping to make things run smoothly.

And last but not least we would like to acknowledge David Harvey, Sue Vanstone and Douglas Graham for initiating this project and organizing the Senior Administrative aspects.

# Executive Summary

Forty participants for the 2 day roundtable included representatives from the Aboriginal community, physicians and other care providers, the Alzheimer Society of Ontario and representatives from selected local Alzheimer Society chapters, the Northern Ontario School of Medicine and Health Canada.

In terms of how ADRD is viewed or experienced in Aboriginal communities, participants described how ADRD is viewed as a more benign, natural progression in life's cycle; with those affected, moving "closer to the creator".

Yet there seems to remain some stigma, embarrassment, and denial when the individual's conditions worsen.

In many Aboriginal communities, family & extended family as well as natural helpers share the responsibility to care for elders at home as long as possible. However, it is recognized that this is growing increasingly difficult as the nuclear family is changing within these communities.

Within Aboriginal communities, there is a greater acceptance of the need to balance traditional and western approaches to care.

Participants spoke of the differences between urban and rural settings as well. In rural settings there is less availability of services on reserve with more family and community supports, whereas in urban settings, there are more system supports and specialized care services with less extended family networks and "sense of community".

**Challenges** particular to the needs of Aboriginal communities included the following:

- Trained Aboriginal service providers; specialist personnel
- Little awareness and visibility of Aboriginal people with ADRD
- Lack of resources to care for people at home; few LTC facilities
- Screening & diagnostic tools not culturally appropriate
- Lack of education materials geared to Aboriginal people
- Service providers lack understanding of history and cultural differences
- Concurrent issues such as mental or chronic illness compound the issue
- Lack of understanding by local political and community leaders

**Service provider needs were described as follows:**

- Cultural sensitivity training along with a cultural competency training manual and "glossary of terms" to facilitate greater knowledge and comfort in working with Aboriginal people

- more trained Aboriginal service providers who speak the language especially as many elders are more comfortable in their original language
- Educational materials developed for and by Aboriginal people using appropriate images, language, modes and technology
- Screening and diagnostic tools which are culturally sensitive
- Statistics for particular risk factors such as diabetes and its link to vascular dementia, or other health risk factors

**Aboriginal community needs** were described as follows;

- **Awareness** – educational materials; efforts to build awareness amongst the community; service providers/agencies and local leadership
- **Trained personnel** - Training manual and/or hands on training program for Aboriginal service providers regarding ADRD
- **Services and supports including:**
  - Earlier intervention - quicker diagnosis coupled with early access to services and education.
  - Home support services
  - Increased support for respite care with more flexibility
  - More support groups in rural settings
  - Access to transportation for those individuals and their families traveling from remote areas to urban areas

Participants stressed the importance of building on existing knowledge and information; working in partnership with others like the Alzheimer Society and Dementia Networks to develop culturally appropriate services, training, tools and resources and seeking best practices from others such as Cancer Care Ontario or the Aboriginal Diabetes Strategy in the development of any action plans or strategies, training and educational materials.

Apart from the importance of addressing cultural competency, in describing their vision of how prevention and care would be structured within communities, participants stressed:

- awareness, early diagnosis and supports in place
- a team supported by video-conferencing which would be used to address any diagnostic issues or specialist shortages
- greater collaboration between organizations like the Alzheimer Society and others like the Heart and Stroke Foundation would be the ideal.

As a first step in working towards this vision, a team was established to begin developing a project to create the needed awareness and educational materials and approaches.

Other important action steps include the dissemination of this report and the expansion of any future roundtables to include more Aboriginal participants.

# Introduction

On March 21<sup>st</sup> and 22<sup>nd</sup>, 2007, a Roundtable Forum was held in Sudbury, Ontario to bring together Aboriginal community representatives, Aboriginal and non-Aboriginal health care providers and others with experience in the provision of Alzheimer and related dementias (ARD) services to discuss ways to improve services to Aboriginal people with Alzheimer Disease and Related Dementias (ARD) who live on and off reserve.

The roundtable forum was financially supported by the Ministry of Health and Long Term Care and sponsored by the following partners:

- Alzheimer Society Ontario
- Mnaamodzawin Health Services Inc.-Manitoulin Island
- Noojmowin Teg Health Centre-Manitoulin Island
- Northern Ontario School of Medicine-Sudbury/Thunder Bay

## **Objectives of the roundtable discussion forum included the following:**

- To explore the prevalence and experience of ARD in different types of Aboriginal communities
- To identify knowledge gaps within Aboriginal communities and the health services serving them about the availability of ARD resources
- To explore the cultural experience of ARD and its significance in Aboriginal communities
- To create an action plan which builds on existing resources and services to increase their effectiveness in serving Aboriginal communities

This report summarizes the discussion and outlines initial recommendations arising from the roundtable forum.

# Background

The prevalence of Alzheimer's disease and related dementias (ARD) within the Aboriginal population is not known but thought to be similar to that of the Canadian population. In Canada, 8% of individuals aged 65 or older are affected by dementia.<sup>1</sup>

Dementia is a syndrome consisting of a number of symptoms that include loss of memory, judgment and reasoning, changes in mood, behavior and communicative abilities. While Alzheimer's disease is the most common form of dementia there are several related dementias including vascular dementia and Korsakoff's syndrome.

Vascular dementia is the second most common cause of dementia after Alzheimer's disease, accounting for up to a third of all dementias. It is thought to be due to impaired blood supply to the brain and causes progressive impairment of the higher functions of the brain such as memory, learning, recognition, fine motor movements and planning. The risk factors for vascular dementia are somewhat similar to those for stroke and heart disease and include diabetes. Thus vascular dementia is a risk to Aboriginal peoples due to the health concerns and high rates of diabetes within Aboriginal communities. In Ontario, the prevalence of diabetes in Aboriginal peoples is three times that in non-Aboriginal Ontarians.<sup>2</sup>

Although not strictly speaking a dementia, Korsakoff's syndrome is a brain disorder usually associated with heavy drinking over a long period of time which causes a loss of short term memory. This is a particular concern within some Aboriginal communities given the higher consumption levels of alcohol which are often at levels considered harmful to health.<sup>3</sup>

The incidence of Alzheimer's disease and related dementias increases as the life span of the population increases as age is the most important risk factor associated with Alzheimer's disease.

Within the Aboriginal population in Canada, there is a trend toward aging, albeit slower than in the non-Aboriginal population. This aging is in large part due to a gradually improving life expectancy and to declining birth rates. The latest projections have indicated that the number of Aboriginal seniors is expected to grow more than two fold by 2017.<sup>4</sup>

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<sup>1</sup> Canadian Study of Health and Aging Working Group. Canadian study of health and aging: study methods and prevalence of dementia. CMAJ 1994; 150:899-913.

<sup>2</sup> B. Shah, et al., "Diabetes and First Nations People," in Diabetes in Ontario: An ICES Practice Atlas, eds. Jan E. Hux, et. al. Toronto: Institute for Clinical Evaluative Sciences, 2003, p. 13.235.

<sup>3</sup> Brady, M. (2000). Alcohol Policy Issues for Indigenous People in the United States, Canada, Australia and New Zealand. Contemporary Drug Problems 27 (Fall): 435-509

<sup>4</sup> A portrait of Canada (2006). Chapter Six: Aboriginal Seniors in Canada Statistics Canada website <http://www.statcan.ca/english/freepub/89-519-XIE/89-519-XIE2006001.pdf>

These changes are beginning to place pressure on existing ways in which we respond to people with ADRD. Traditional responses will be strained as numbers increase and populations disperse.

This is further impeded by lack of understanding of different cultural experiences and the appropriate transfer of knowledge. The competency of providers to transfer information and knowledge can be increased with the result that people will be better served.

## Participants and their objectives

Forty participants including Aboriginal urban and rural community representatives, physicians, specialists and other care providers, representatives of the Alzheimer Society of Ontario and selected local Alzheimer Society chapters, the Northern Ontario School of Medicine and Health Canada participated in this 2 day roundtable. A full list of participants is included in Appendix A.

Given the diverse background and interests of participants, the forum was recognized as the beginning of ongoing dialogue and viewed as an opportunity to:

- Network, share experiences, knowledge and information
- Listen & learn, offer new ideas; begin process of dialogue
- Learn more about First Nations and Aboriginal people and cultural differences in approaches to ADRD
- Learn more about ADRD, its impact on individuals, families and communities as well as ways to assist and offer better care
- Learn about what is needed, what is available and what can be done
- Learn how best to reach out to Aboriginal communities and disseminate information
- Learn how training and educational materials can be made more appropriate and resources more helpful
- Learn how to improve physician education and instruction in this area
- Explore challenges in providing care to persons with dementia in Aboriginal communities
- Initiate steps towards the development of a strategy

# How is ADRD viewed in Aboriginal communities?

Participants discussed how ADRD is viewed/experienced differently within Aboriginal communities and shared the following views:

- ADRD is viewed in a more benign fashion as some form of natural progression in life's cycle.
- In some communities, those experiencing ADRD are considered as moving "closer to the creator" as their life completes its closing passages and the life cycle reverses as they revert to childhood ways and greater dependency.
- The return of old memories and childhood traits is viewed in a respectful and positive manner, with those affected, accepted the way they are.
- The approach to the disease is less "combative" but more recognized as a need for balanced approach
- Yet there seems to remain some stigma, embarrassment, and denial when the individual's conditions worsen.

# How do Aboriginal communities currently respond?

Participants shared their experiences and understanding as to how Aboriginal communities currently respond to the needs of community members affected by ADRD.

- The sentiment of “it takes a community” is taken to heart especially in small First Nation communities.
- Family & extended family as well as natural helpers share an ingrained responsibility to care for elders at home as long as possible yet it is recognized that this is growing increasingly difficult as the nuclear family is changing within these communities.
- All family including children are included in end of life passages and ceremonies and children are not shielded from death or serious illness.
- In some communities, such as those that are Haudonosaunee, daughters assume a larger role and greater responsibilities in caring for elder family members and those who are ill.
- While there may be limited awareness and understanding of ADRD within communities, no definitions, diagnosis or label is required for those who want help.
- There is a greater acceptance of the need to balance traditional and western approaches to care.

# How does this differ in urban and rural settings?

Participants shared their views as to how community responses within an urban context contrast with those in a rural setting.

- In urban settings Aboriginal people were perceived as more apt to seek out services.
- More system supports are available in urban settings including translation, transportation, and support groups.
- The “sense of community” is perceived as lost in larger urban centres.
- More natural helpers and care givers are available in rural settings.
- It is important to recognize that culture is always with the person no matter the setting

This discussion raised an important quality of life question or dilemma faced by families who are seeking care to improve the comfort of their loved ones:

- In rural settings there is less availability of services on reserve but more family and community supports.
- In urban settings, there are more specialized services but loss of extended family networks, community and the familiar.

It is clear that more supports, resources must be made available both on & off reserve.

# Challenges particular to the needs of Aboriginal communities

Participants described some key challenges which are particular to Aboriginal individuals, families and communities and affect their capacity to respond:

**HUMAN RESOURCES** – there is a lack of Aboriginal service providers who are trained in this area as well as a lack of access to specialist personnel with expertise in this area

**AWARENESS** – There seems to be limited awareness and little to no visibility of Aboriginal peoples affected with ADRD.

**RESOURCES** - Lack of resources to care for people at home and few long term care facilities on First Nations or available locally. Options for care are not as readily available.

**SCREENING AND DIAGNOSIS** – The screening and diagnostic tools typically used may not be culturally sensitive.

**EDUCATION** – There is a lack of educational materials geared towards the needs of Aboriginal peoples.

**CULTURAL COMPETENCY** – Service providers are hindered by limited understanding of the complete history. This includes not only the individual patient's medical history but their "life's story" supported by a general understanding of the community's and people's history.

**PREVENTION** – It is recognized that prevention is very difficult and often organizations "spend money on effect but not the cause".

**CONCURRENT ISSUES** - There may be mental health problems or chronic diseases which compound the problem or erosion of family which impacts on the patient's care and outcomes.

**POLITICS** – In general, it was recognized that there is a lack of understanding on the part of politicians and leaders and consequently less of priority placed on addressing ADRD.

# Service Provider Needs

In reflecting on and discussing the question: “What do practitioners and service providers need in order to more effectively respond?” participants described the following as areas of need for service providers whether they be Aboriginal or non-Aboriginal:

## Building cultural competence

- Cultural sensitivity training for mainstream service providers, care givers and workers in Long Term Care facilities etc.
- A cultural competency training manual and “glossary of terms” to facilitate greater knowledge and comfort in working with Aboriginal people

It is important to recognize that the culture of Aboriginal groups is different across geographic areas.

## Working with Partners in Care

- more trained Aboriginal service providers who can work collaboratively with other care providers as “situational experts”,
- people who speak the language especially as many elders are more comfortable in their original language

## Culturally Appropriate Tools

- Educational materials which have been developed in collaboration with Aboriginal people using appropriate images, language, modes and technology
- Screening and diagnostic tools which are culturally sensitive

## Research

- Statistics for particular risk factors such as diabetes and its link to vascular dementia, or other health risk factors

# Community Needs

In reflecting on the question: “What do Aboriginal communities need to support individuals and families affected by ADRD?” participants described the following as areas of need:

## Awareness & Education

- Develop education and training materials that are:
  - culturally appropriate ie developed for and by Aboriginal people
  - using images, photography and artwork which reflect Aboriginal peoples
  - use appropriate language ie First Nations languages and colloquialisms where possible, plain language which is non-technical jargon-free
  - utilize all modes of delivery and technology ie print & electronic
  - targeted to various age and risk groups
- Develop a training manual and/or hands on training program for Aboriginal service providers about ADRD
- Build community awareness of ADRD by providing information at appropriate venues such as community events, pow wows etc.
- Ensure health agencies and health service providers have an awareness of services available on and off reserve such as what agencies like Alzheimer Societies can offer.
- Educate and inform local community leadership

## People

- Trained Aboriginal service providers; provide hands on training in First Nations
- Care givers and service providers who speak the language

## Services and Supports

- Earlier intervention - quicker diagnosis coupled with early access to services and education.
- Home support services
- Increased support for respite care with more flexibility
- More support groups in rural settings
- Access to transportation for those individuals and their families traveling from remote areas to urban areas

# Embedded in the response

Participants recognized that there is much that can be accessed and adapted from other areas. As such it would be important to:

- Build on existing knowledge and information
- Work in partnership with Alzheimer Society to develop culturally appropriate services, training, tools and resources
- Network with others who can provide services such as the Dementia Networks
- Seek best practices from others - eg Cancer Care Ontario, Aboriginal Diabetes Strategy in the development of any action plans or strategies, training and educational materials

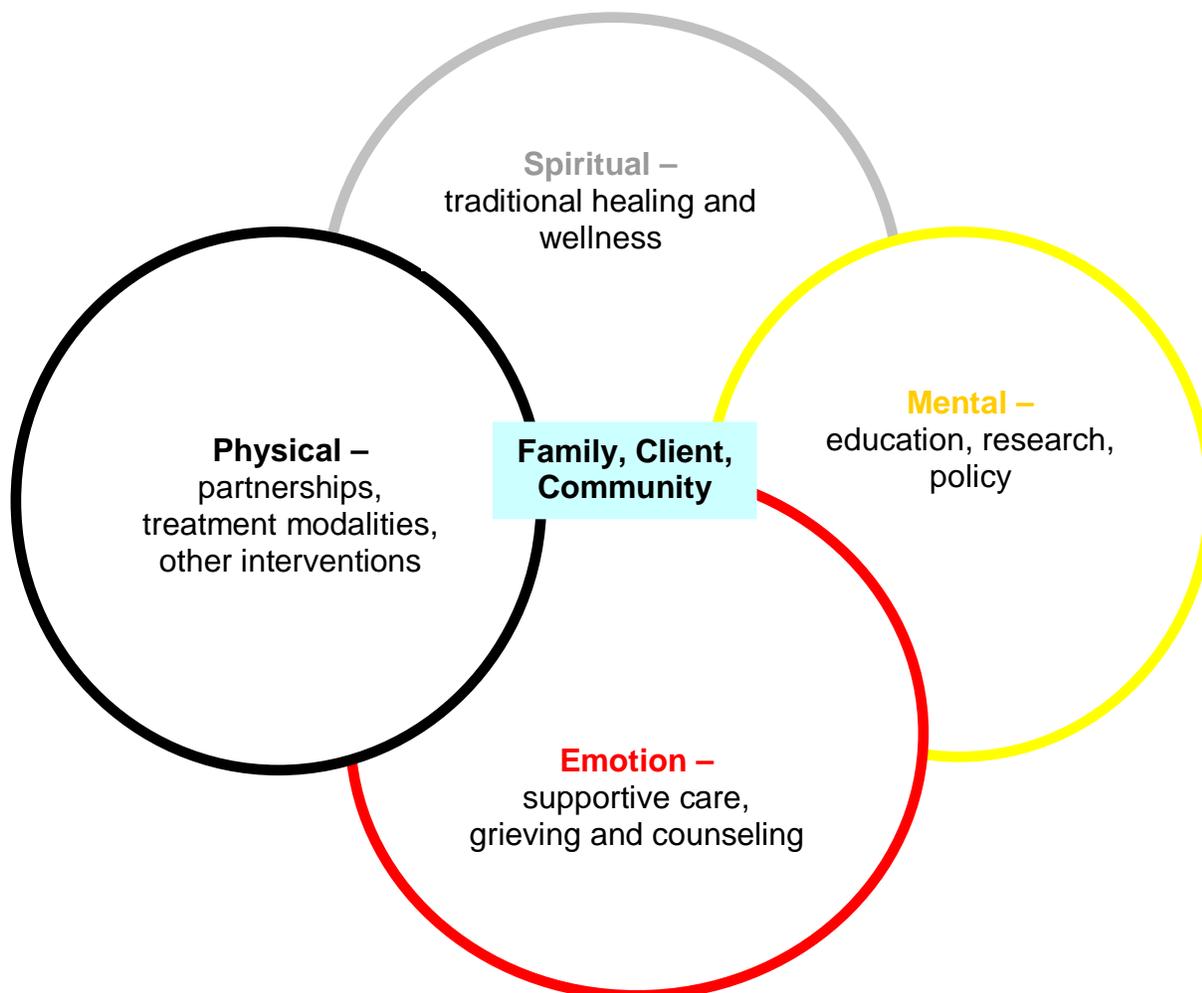
In short, mine the network of potential partners and link/coordinate with others who share the same aims.

# Future Vision

Participants then turned their attention to an idealized vision of how care and ultimately, the quality of life could be improved for Aboriginal people confronted with ADRD. Elements of this vision include:

- ✓ Early diagnosis would be the norm with support for individuals and families in place soon after.
- ✓ This would be augmented by early engagement of families and communities to improve quality of life which would be similar to “First Link”
- ✓ A team would be established for dementia diagnosis to alleviate shortage of resources, geographic and demographic challenges along with video conferencing to access specialist consultations with widespread acceptance and comfort levels in their usage.
- ✓ Education on ADRD would be taking place within the community and awareness would begin amongst younger people at the elementary school level.
- ✓ Greater collaboration and partnerships amongst organizations like Alzheimer Society, Diabetes Association and the Heart and Stroke Foundation would ensure a seamless approach to education and awareness and address common risk concerns.
- ✓ There would be more flexibility as to how care is provided and “community” would be defined as where the individual lives ie seamless access or consistent care is provided regardless of on or off reserve status.
- ✓ Strong partnerships would be in place to support the continuum of care.
- ✓ Practitioners would have and be trained in the use of culturally appropriate diagnostic tools.
- ✓ Cultural competency training would be in place for clinicians and other mainstream service providers.
- ✓ Culturally appropriate language would replace the technical terminology and jargon.
- ✓ Life long care plans would be developed and reviewed with community health centre support.
- ✓ Culturally appropriate activities and programs along with support systems are in place for families.

In defining their vision, participants also devised a visual representation of the **“CIRCLE OF CARE”** which places the individual, family and community at its centre.



# Priority Areas for Future Action

To address key areas of need and initiate steps toward this vision, participants prioritized four (4) areas for action. These are:

- **cultural sensitivity training for mainstream service providers**
- **training in ADRD for Aboriginal service providers**
- **culturally appropriate educational materials**
- **establishing partnerships with the Alzheimer Society**

Recognizing that a number of these areas are complementary it was decided that initial steps would include:

- **Outlining goals, objectives and a plan of action**
- **Developing a Terms of Reference for the group**
- **Suggesting additional resource persons or participants to be invited to the working group**
- **Focusing on Ontario as the initial pilot project area**

Establishing a working group entitled initially “Team Education” comprised of

1. Mary Schulz, Senior Manager, Alzheimer Society of Canada– Chairperson
2. Cathy Conway, Alzheimer Society Ontario
3. Kelly Poulis, Six Nations Health Services
4. Jeff Renaud, Alzheimer Society of Brant
5. Maureen Prairie. Alzheimer Society of Thunder Bay
6. Sara Johnson, Ontario Federation of Indian Friendship Centres
7. Shubie Chetty, First Nation and Inuit Health, Home & Community Care, Ottawa
8. Andrea Coady, First Nations and Inuit Health Regional Home & Community Care, Ottawa
9. Bruce Pope, Mnaamodzawin Health Services

# Next Steps



**Convening a meeting of the work group within the next 3 months**

**Share this report to further dialogue and discussion**

**Stimulate more participation and feedback from a wider audience amongst Aboriginal communities**

**What did you like most about this roundtable session?**

A variety of participants with a diverse background were allowed to be open with their dialogue to discuss working experience with individuals diagnosed with Alzheimer and also allowed the participants to share their life experiences. The discussions around aboriginal cultural and traditions within aboriginal communities were eye opening. The small groups helped everyone to feel comfortable with sharing knowledge of actual experiences. Understanding of the disease and related dementias is a long path but the dedication and passion expressed by everyone present will assist with the big picture. Presentation from Dr. LeClair, Stella Corbiere, and Marjory Shawande provided a clear understanding of the western and traditional concerns related to Alzheimer’s Disease and Related Dementias. The facilitator kept adhering to the agenda which allowed for movement to share information in a timely manner.

**What did you like least?**

The meeting room was not as comfortable as the temperature and the chair were uncomfortable. It was difficult to hear at times. More representation from the aboriginal population would have been better. Not being prepared to participate in open dialogue as a participant but later felt comfortable with the given dialogue; understanding that all input is respected. Needed info mailed out ahead of time to read (eg. Educational materials).

**Are there particular topics, speakers, activities, participants you would have to see included or considered for any future roundtables? Please elaborate.**

- More grass root politicians should be present (local MP, deputy minister) probably not realistic but practical.
- Display of existing materials, we could have provided lots.
- Would be interesting to hear from a family affected by ADRD in First Nation community, (family that is willing to share their experiences with the group).
- More aboriginal agencies - front line workers.
- Have information on cultural history of aboriginal people
- We need to do our grass roots work before we can go to the political decision makers.
- This was the first step of many needed. The group showed passion for the topic ADRD.
- The group needed a bit of fundamental endorsement on aboriginal issues as a starting point - start by providing “competency training for those at the table o/c they will be our champions.
- Nursing Home & Community Nurses - personal support nurses.
- Keep including Aboriginal Elders facilitators and people with Traditional. knowledge Same as this session
- To have the facilitator - Mariette McGregor-Sutherland be invited to return to work with the group. Excellent facilitation skills; summarize of each session. Invite the key players to the table from First Nation & Health Access Centres

- Good references to learn more about Aboriginal traditions, history, culture etc,
- It would have been feasible for someone to do an opening song and drumming to demonstrate the spirituality of aboriginal people.
- Further roundtables to continue the work which was started here

**Did you find this meeting productive in relation to your role? If yes, please describe. If no, please tell us how it can be improved.**

Yes, the participants felt the goal before them was accomplished and recognize the hard work ahead to continue educating and dialogue with the partners to address First Nations people. Enough information was shared to contribution to our existing workplans to take home and begin to implement steps to assist with educating the community members in our regions.

Appendix “B” LIST OF PARTICIPANT

Kit Julian	Alzheimer Society Ontario-Horfolk
Mariette Kozicki	Alzheimer Society Ontario-Sudbury
Patricia Montpetit	Alzheimer Society Ontario-Sudbury
Mary Schulz	Alzheimer Society Canada
Maureen Pierre	Alzheimer Society Ontario- Thunder Bay
Cathy Conway	Alzheimer Society Ontario
Jeff Renaud	Alzheimer Society Ontario-Brantford
Rev. Dr. Dick Schonewille	Alzheimer Society Ontario-Kenora and Rainy River
Arlene Gear	Alzheimer Society Ontario-Sault Ste. Marie
Linda Sullivan	Alzheimer Society Ontario-Sault Ste. Marie
Connie Conrad	Alzheimer Society Ontario-Sudbury
Sandra Gagnon	Alzheimer Society Ontario-Timmins
David Harvey	Alzheimer Society Ontario
Jacquie Butler	Alzheimer Society Ontario
Stella Corbiere	Elder- Wikwemikong
Mariette Sutherland	Facilitator – Whitefish River
Shubie Chetty	First Nation Inuit Health – Ottawa
Andrea Coady	First Nation Inuit Health – Home & Community Care – Ottawa
Beverly Nahwegahbow	Mnaamodzawin Health Services-Manitoulin
Bruce Pope	Mnaamodzawin Health Services-Manitoulin
Douglas Graham	Mnaamodzawin Health Services-Manitoulin
Glenn Hallett	Mnaamodzawin Health Services-Manitoulin
Brenda Roy	Mnaamodzawin Health Services-Manitoulin
Marjory Shawande	Noojmowin Teg Health Centre-Manitoulin
Lilly Couchie	North Bay Indian Friendship Centre
Marilyn Proulx	Northeast Mental Health-Manitoulin
Dr. Koka	Northeast Mental Health-Sudbury
Marion Maar	Northern Ontario School of Medicine-Sudbury/Thunder Bay
Kristin Jacklin	Northern Ontario School of Medicine-Sudbury/Thunder Bay
Marie Vezina-Topolnicky	Northern Ontario School of Medicine-Sudbury/Thunder Bay
Karen Babamikawe	N'Swakamok Native Friendship Centre-Sudbury
Tony Tyson	N'Swakamok Native Friendship Centre-Sudbury
Sara Johnson	Ontario Federation of Indian Friendship Centres-Toronto
Dr. Andre L. Hurtubise	Physician-New Liskeard
Dr. Jeffrey Roy	Physician-Manitoulin
Dr. Kenneth LeClair	Providence Continuing Care Centre-Mental Health
Kelly Poulis	Six Nations Home & Community Care
Mary Jo Wabano	Wikwemikong Health Centre

## **AGENDA**

### **Wednesday, March 21<sup>st</sup>, 2007**

- |                     |   |
|---------------------|---|
| 8:00 am – 8:30 am   | Registration, coffee, networking  |
| 8:30 am – 8:45 am   | Opening Prayer, Stella Corbiere, RN   |
| 8:45 am – 9:00 am   | Welcoming Remarks – David Harvey, Alzheimer’s Society of Ontario and Douglas Graham, Mnaamodzawin Health Services   |
| 9:00 am – 9:30 am   | Roundtable Introductions<br>Sharing Objectives  |
| 9:30 am – 9:50 am   | Alzheimer’s Disease and Related Dementias – a brief overview<br>Dr. Kenneth Le Clair<br>Providence Continuing Care Centre<br>Mental Health Services, Kingston<br><br><i>An understanding of the disease and related dementias as well as the current literature is instructive for all.</i>   |
| 9:50 am – 10: 15 am | The Alzheimer’s Society of Ontario – at a glance<br>David Harvey (or alternative presenter)<br><br><i>The Alzheimer’s Society of Ontario has many resources to assist individuals, families and communities. Its various chapters have initiated outreach to Aboriginal communities.</i>  |
| 10:15 am – 10:30 am | Refreshments and Networking Break   |
| 10:30 am – 11:00 am | Aboriginal perspectives on dementia and care<br>Stella Corbiere RN (retired) and Marjory Shawande, Traditional Coordinator, Noojmowin Teg Health Centre<br><br><i>Aboriginal community perspectives and teachings on life stages, the medicine wheel and holistic health lend much to the care of community members affected by ADRD.</i>   |
| 11:00 am – 12:00 pm | Group discussion – Current Situation<br>Two groups will form to discuss the following questions. A reporter and recorder will be designated within each group. The facilitator will circulate between both groups.<br><br><i>Participants are encouraged to share their experience, perceptions, concerns and/or questions related to how ADRD is viewed within Aboriginal communities and how communities respond to the needs of individuals and families affected.</i> |

12 pm – 1 pm	Lunch, networking
1:00 pm – 1:30 pm	Groups report – Current situation
1:30 pm – 2:30 pm	Group Discussion – Unique needs  Two groups will form to discuss the following questions. A reporter and recorder will be designated within each group. The facilitator will circulate between both groups.  What do Aboriginal communities need to support individuals and families affected by ADRD in their communities? What do practitioners and service providers need in order to more effectively respond? Are there gaps that currently exist that would need to be addressed? Areas to be discussed could include: primary care; long term care; education or training for practitioners and providers; awareness and information for communities; caregiver needs and support networks; specialized services, further research etc.  <i>Participants will be encouraged to examine potential areas of need and elaborate as to how this may differ from needs in the mainstream populations.</i>
2:30 pm – 2: 45 pm	Networking and Refreshments Break
2:45 pm – 3: 15 pm	Groups Report – Unique needs
3:15 pm – 3:45 pm	Plenary Group Discussion - Future vision  What is the idealized version of how care and ultimately, the quality of life is improved for Aboriginal people confronted with ADRD. How does this look when it is actualized in communities? Who is involved, what is their contribution? Etc.  <i>Participants will be encouraged to describe a collective vision of how, working together, the elements are in place to improve the quality of life and enhance care of Aboriginals living with ADRD.</i>
3:45 pm – 4:00 pm	Wrap up and overview of Day Two Agenda Closing Prayer
4:30 pm – 5:30 pm	Tour of Sudbury Manitoulin Alzheimer's Society Chapter office
6:30 pm – 7:00 pm	View Crime Scene
7:00 pm – 8:00 pm	Dinner: Simon's Café & Deli
8:00 pm – 9:00 pm	Solve the Mystery

## Thursday, March 22<sup>nd</sup>, 2007

8:00 am – 8:30 am	Coffee and networking
8:30 am – 8:45 am	Opening
8:45 am – 9:30 am	Presentation of summary of yesterday's proceedings
-	Differences
-	Current situation
-	Gaps, challenges
-	Areas of need
-	Vision of improved care

9:30 am – 9:45 am      Dot-mocracy exercise to prioritize areas for actions

9:45 am – 10: 15      Group discussion  
Arriving at consensus concerning 3 or 4 priority areas

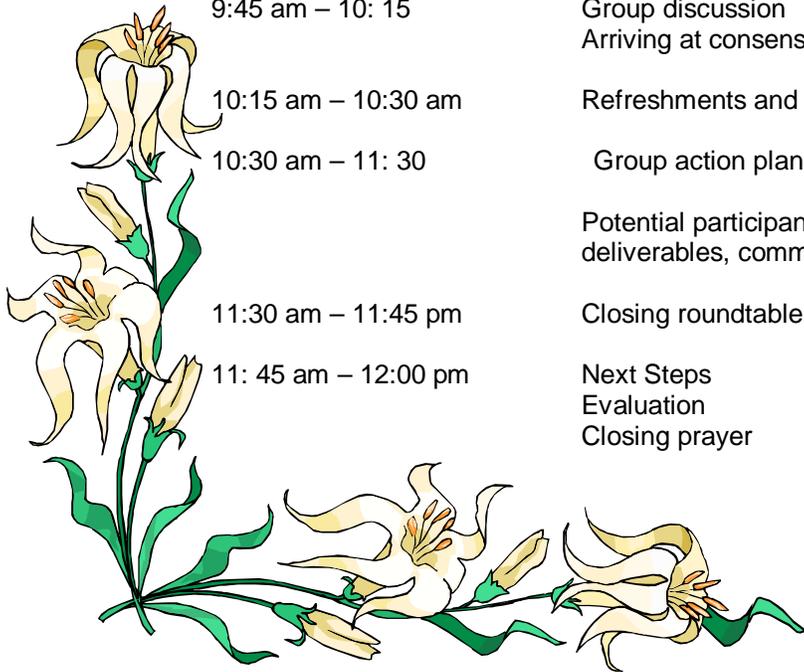
10:15 am – 10:30 am      Refreshments and networking break

10:30 am – 11: 30      Group action planning in 3 or 4 areas selected

Potential participants, Key next steps, timelines and deliverables, commitments by participants

11:30 am – 11:45 pm      Closing roundtable

11: 45 am – 12:00 pm      Next Steps  
Evaluation  
Closing prayer



## Appendix “D” TERMS OF REFERENCE

### GOAL

#### Goal

To improve services to aboriginal people with Alzheimer Disease and related dementias (ADRD) who live on and off reserve by bringing together individuals who are aboriginal, serve aboriginal people and persons involved with Alzheimer services to share information and formulate a plan of action based on recent initiatives and methodologies within the health and social services sectors.

#### Assumption

The prevalence of ADRD within the aboriginal population is thought to similar to the entire population in Canada. The incidence is increasing as the life span in both populations increases. These changes are placing pressure on existing ways in which we respond to people with ADRD. Traditional responses are strained as numbers increase and populations disperse. The transfer of knowledge between cultures is impeded by a lack of understanding of different cultural experiences. The competency of providers to transfer information and knowledge can be increased with the result that people will be better served.

### SPONSORS

1. Alzheimer society of Ontario and the Alzheimer Society of Sudbury-Manitoulin
2. Mnaamodzawin Health Services Inc.
3. Northern Ontario School of Medicine
4. Noojmowin Teg Health Centre

### ROUNDTABLE

- To explore the prevalence and experience of Alzheimer’s Disease and Related disorders in different types of aboriginal communities
- To identify knowledge gaps within aboriginal communities and the health services serving them about availability of Alzheimer’s disease and Related Disorders resources
- To explore the cultural experience of Alzheimer’s Disease and Related Disorders and its significance in aboriginal communities
- To create an action plan which builds on existing resources and services to increase their effectiveness in serving aboriginal communities

### ANTICIPATED ACTION PLAN

We anticipate that the participating leaders from the aboriginal community, aboriginal services, primary care and the “ADRD” sector will want to arrive at specific actions plans and may consider the following areas:

#### Provider/Family Education

To educate people who serve aboriginal people with ADRD about the disease and care strategies. This project will be based on the PIECES and U-FIRST methods (see attached) and the activities will involve:

- make training and materials more culturally appropriate
- Increasing the cultural competence of person who will do the training

Specific activities would include:

1. conducting pilot training of service providers, in a dialogue form to transmit information but also critique content and method from a cultural perspective.
2. revising training methods, content and materials based on pilot (language).
3. identify additional tools which may need development or revision

#### Primary Care Project

To work with primary care providers to aboriginal people:

- to develop expertise in using existing tools to screen, diagnose and treat persons with AD/DRD
- to study the application of these tools to identify any cultural issues which may influence accuracy
- to modify and test changes in tools, etc.

#### Cultural Competency

To develop mechanism by which the Alzheimer Society chapters and other resources, e.g. Psychogeriatric consultants, can better serve aboriginal communities:

- developing cultural competency within the chapters
- piloting specific collaborative projects with aboriginal communities and services

Appendix "E" DR. LE CLAIR PRESENTATION

## Alzheimer's Disease and Related Dementia

What New; An Old Disease with New Hopes, New Approaches and New Horizons through Understanding

What The Research Tells us  
Sudbury 2007

## The Journey Keys to Understanding and Change

- Experience
- Evidence
- Exchange

## The Lens For Discovery and to Determine Direction (Evidence)

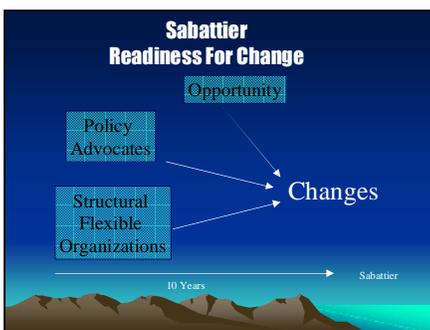
Lens 1; Challenges for the Individual and Family

Lens 2; Challenges for the Practitioner and Health System, Community

Lens 3,4,5; Challenges to the Researcher, the Educators, Community Leaders and Planners (adapted Raycroft et al)

## Changes

- The Evidence, the Context, the Facilitation
- The Time, and People (Sabattier and Rogers)



## The Evidence and Realities Transforming Our Thinking and Our Approach -- The Three Journeys

Outline

- Ghosts of the Past (Journey over time 18<sup>th</sup>-21 century)
- Realities of the Present (Journey of Discovery: Medical Understanding and Challenges over Course of the Disorder)
- Trends of Future (Journey Beyond the Disorder and the Medicine to the Person, Family, Community)

## The Ghosts of the Past Journey over the Centuries

- The Stigma
- The 18<sup>th</sup> Century Health Care

## Seniors' Double Jeopardy *"Ageism and Dementia"*

*The Many Hidden Faces, The Collective Opportunities*



Many of our senior citizens will live their final years in despair and suffering without any appreciation of their affliction or the understanding and comfort of those dear to them.



NIMH Consensus Conference

## Reflections

Old ..... 2 words to describe

Demented ..... 2 words to describe

Old and Demented... 2 words to describe

*"It will affect most of us"*

## Stigma

Negative attitudes

- Failure of Diagnosis
- Lack of treatment, medical/surgical conditions
- Involving people in decisions
- Premature placement

Benbow S.  
Hosp. Medicine  
2000 vol 6, no.3

## A Framework for Stigma and Dementia: The 4 S's




## The Evidence/Reality

### The Ghosts of the Past

- The Stigma
- The 18<sup>th</sup> Century Health Care in the 21<sup>st</sup> Century (a disaster for dementia care)

## The System; We Live and Work In



"The Situation is distorted when the Population is defined as the Problem.

"Rather the Problem is best defined as those factors which have created the gulf between the needs of the people and the approaches to address these needs."

Cohen

## Traditional Acute Care Organization and Culture

- Acute problems
- Emphasis on triage and patient flow
- Short appointments
- Diagnosis and treatment of signs and symptoms
- Reliance on laboratory investigations and prescriptions
- Brief didactic consumer education
- Consumer initiated follow-up
- Emphasis on provider - not system - behaviour

Wagner 1998

## Focus is on management of acute problems

- Treat only those people who reach us
- Can't identify problems earlier
- No prevention of episodes/recurrence
- No consistent after-care
- Lack of necessary services in clinics i.e. work
- Disconnected system
- Not consumer-driven

## Transformation

- |   |   |
|---|---|
| • Prevention not a priority                 | Prevention all points of life continuum   |
| • Solo Provider                             | Integrated interdisciplinary care (TCAM)  |
| • Provider disease centered                 | Person, Relationship centered             |
| • Reactive and episode                      | Proactive complex continuing              |
| • Limited role of individuals in management | Individuals, informed active participants |

## The Second Journey: Journey of Discovery

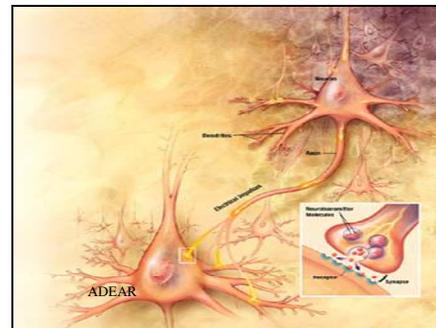
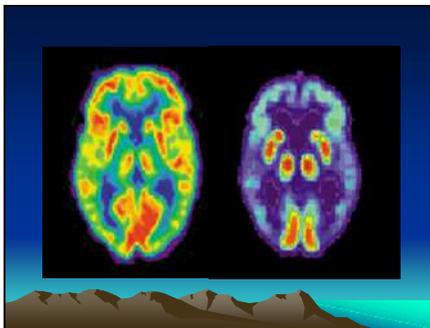
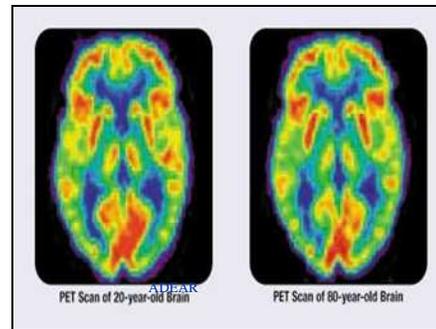
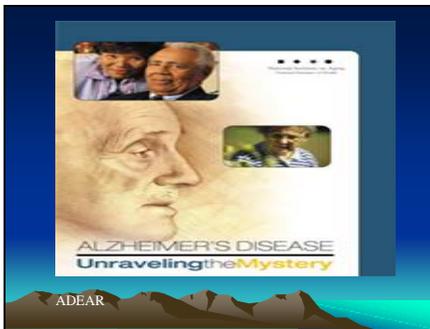
- The Stigma
- The 18<sup>th</sup> Century Health Care

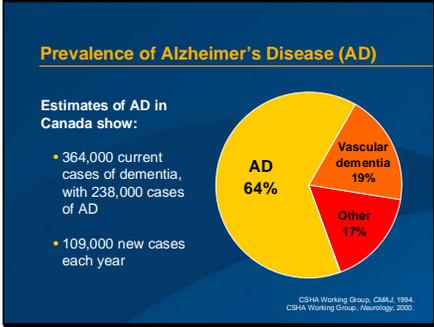
### The Second Journey

- The Medical Understanding, the Types, the Course and Characteristics

## The Understanding from Normal Senility to Alois Alzheimer to Present Understanding

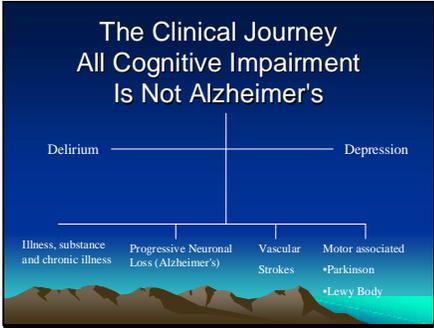
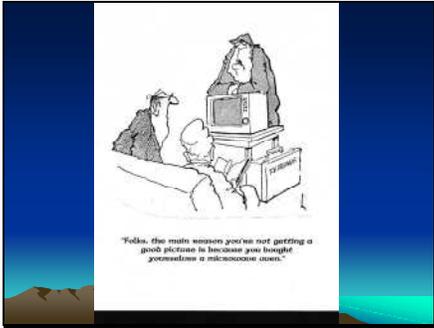
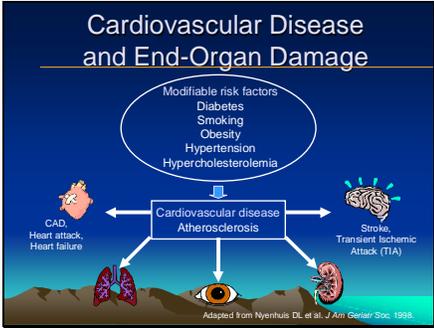
- Brain Changes
- Cell Changes (Neuron and Transmitters ie brain messengers)
- Changes in Thinking (cognition), Feeling, Perceiving and Behaviour (ABC)





- ### Types of Dementia (More than 50 Reasons)
- Types of Dementia
- Alzheimer's
  - Vascular
  - Alcohol Related
  - Lewy Body
  - Associated with Neurological Disease and Front Temporal

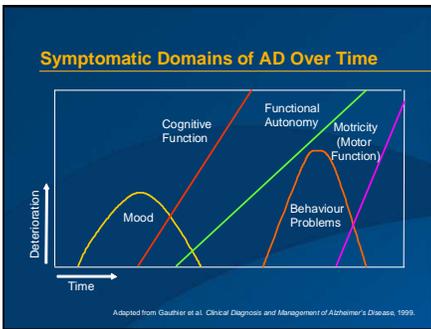
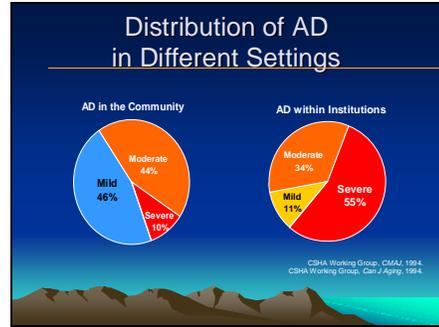
- ### A Word Re Vascular/ Mixed Dementia
- Increasingly recognized
  - One will Contribute to the other
  - Predicted to Increase
  - A vehicle to Prevent and Treat



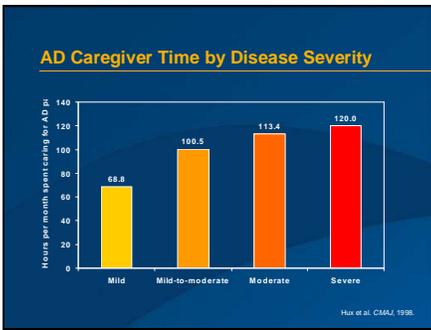
### Functional Assessment Staging (FAST)

Raisberg B et al. Psychopharmacol Bull. 1988.

FAST Scale Stage	Characteristics
1 Normal adult	No functional decline.
2 Normal older adult	Personal awareness of some functional decline.
3 Early AD	Noticeable deficits in demanding job situations.
4 Mild AD	Requires assistance in complicated tasks such as handling finances, planning parties, etc.
5 Moderate AD	Requires assistance in choosing proper attire.
Moderately-severe AD	Requires assistance dressing, bathing, and toileting. Experiences urinary and fecal incontinence.
7 Severe AD	Speech ability declines to about a half-dozen intelligible words. Progressive loss of abilities to walk, sit up, smile, and hold head up.

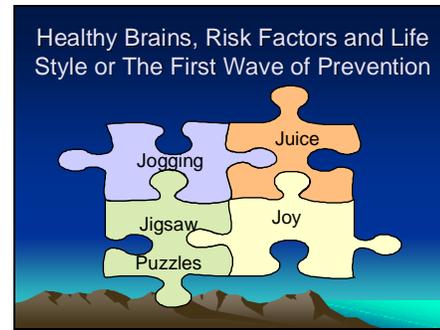
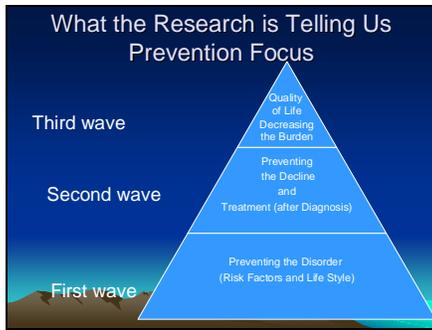


- ### A Focus on Brain and Behaviour
- 70-80% during Course of Disorder
  - Need for Understanding, Responsive Not Purposeful (willful i.e., Time Warp, PTSD, & the 7 A's)
  - Often Not due to the Dementia (Diagnostic Overshadowing)



### Heads up for Healthier Brains, Putting the Research in a Preventive Framework

(Alz Society and Jack Diamond)



### Jogging

- The NUNS study and Vascular Risk Factors
- Uncontrolled Hypertension in mid life 3x our risk of cognitive decline (Cherkov)
- Regular Exercise; 3x/week, 40% less likely to develop Alzheimer's

### Juice or We are What we Eat

Study

- 1836 subjects followed up to 10 years free of dementia 1992-1994
- 2 year follow up till 2001

Outcome

Alz reduced 76% drank vegetable juices more 3x week compared to once (why Antioxidants)

(Dai Am J. of Medicine Sept 2007)

### Joy

- Increase Leisure Activities and Social Network can decrease Risk of Cognitive Decline 2x (Cherkov)
- Stress; uncontrolled stress can double risk of memory decline
- Extremely optimistic people are 45% less likely to die of heart disease and other causes (Arch of General Psych)

### Jigsaw Puzzle

Baycrest Centre (Winocur/Stuss)

Study Age Range 71-87

- Free of Neurological or psych illness
- Daily logs, breaking up task, talk about loss of confidence
- Categorization, spaced retrieval, story making, associations, visual imagery

Results; 15 to 40% improved Memory

## Jigsaw Puzzle

- Monolingual vs. bilingual (M. Freedman)
- Decrease risk of memory loss with life long habit of reading and learning (Cherkov)
- New York Times Crossword 4 days a week has almost 50% lower risk of Alzheimer's (Dr. Zaldy Tan)

## So What am I Going to Do?

First Wave

### Working Towards

- No stress — Joy
  - Rich = connected
  - A fantastic toned body — Jogging
  - Moving from neighborhood with MacDonald's to Produce Market — Juice
  - Doing crossword puzzles and learning a new language — Jigsaw puzzles
- (Note: Doing crossword puzzles burns 1.5 calories/min)

## The Second Wave of Prevention Medical Research

Or Improve/Slow, Stop, Mop up, Repair

### Improve

- Drug Treatments cholinergic and glutamergic
- Diabetes of the Brain (glitazones)

### Stop

- Cholesterol (statins); Decrease cholesterol reduces A Beta amyloid
- Alzhemed/Flurizan, Secretase inhibitors, stop the sticking

### Mopping up

- Ubiquitin
- Vaccines (animal) cytokine pretreatment modified A Beta

### Repair

- NGF Nerve growth factor

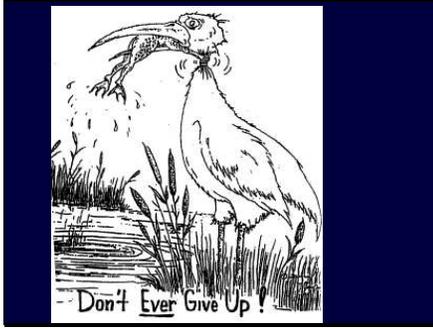
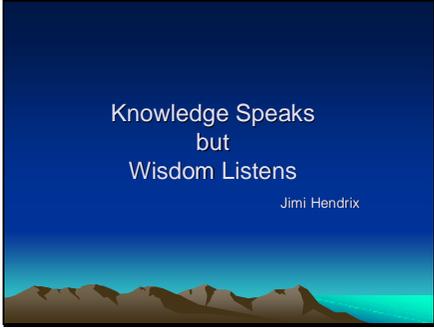
## The Third Journey; Beyond the Medicine and the Disorder to the Person, the Family, and Community

- Relationship-centered Approach
  - Access; Society (stigma) and Community (driving)
  - Access; Health Care 18<sup>th</sup>- 21<sup>st</sup> century; FHT/First Link
- Knowledge and Change; Individual, Health Care System, Organization and Community

## Summary

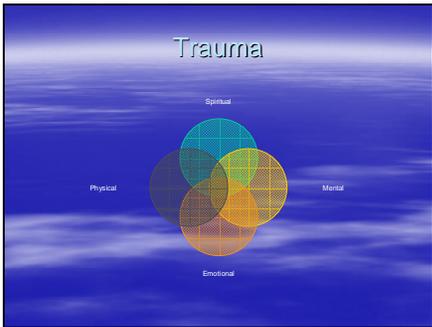
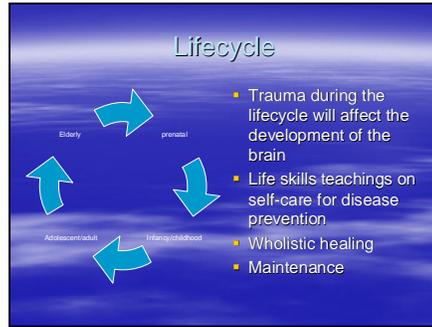
### Thinking Differently; Making a Difference

- 18<sup>th</sup> Century Health Care in the 21<sup>st</sup> Century
- From Treatment of Disease to Prevention
- Challenge and Change at Individual, Health System Organization, Community Level



Appendix “F” ABORIGINAL PERSPECTIVE

Anishnawbe approaches  
for Alzheimer’s disease  
and Related Disorders



- ### Meegwetch
- Noojmowin-Teg Traditional Program
  - Stella Corbiere, Traditional Teacher
  - Marjory Shawande, Traditional Coordinator



Susan Vanstone  
Manager, Aboriginal Health Initiatives  
MOHLTC  
80 Grosvenor Street  
Toronto

January 8, 2007

Dear Ms. Vanstone,

Thanks so much to you and your colleagues for recently meeting with Doug Graham and I to discuss some thoughts on exploring the issue of health services to aboriginal people with Alzheimer Disease and related disorders (ADRD).

The Alzheimer Society and its partners have made significant progress over the past few years, with the help of government to reach out and educated the public and service providers about ADRD and effective service. We are cognizant, however, of our shortcomings in respect to reaching aboriginal people and those who provide services to them.

We know that the life-span of aboriginal people is increasing, fortunately. As age is the greatest risk for ADRD, we believe that its incidence is rising among aboriginal people. A preliminary literature search which we conducted reveals little about services of the kind needed. Doug and I conducted some 'key informant' research and these people agreed that the incidence of the disease was increasing and there were learning and service gaps apparent.

We are seeking to convene a 'roundtable' to bring together people from varying perspectives to discuss this issue and to create some action plans that we would work to implement. You will find attached an outline of our roundtable and an associated budget. It is our hope that the MOHLTC will grant \$30,000 in funding for our 'roundtable' discussion. We are pleased to advise you that the Northern Ontario School of Medicine has joined us as a partner and offered their facilities for the event and will also contribute to its design and the resulting report. The other sponsors are the Alzheimer Society of Ontario, Alzheimer Society of Sudbury-Manitoulin, Mnaamodzawin Health Services Inc., and Noojmowin Teg Health Centre.

Our proposal includes a draft list of invitees. It has been prepared with concern for including a full spectrum of groups, services and experts. We are open to any input which you may have in this regard.

Susan, time is an important issue for us. We are available anytime to provide more information, discuss modifications to our proposal or the budget. We will continue our planning process in terms of detailing the day, sending out a 'heads-up' notice to potential participants and otherwise moving forward. We will be back in touch with you the week of January 22.

Yours very truly,

Linda Stebbins

Douglas Graham