

# ***Collaborative Research Grant Initiative: Mental Wellness in Seniors and Persons with Disabilities***

## ***Ideas Fund Report***



Promoting Early Identification and Prevention of Delirium in at Risk Older  
Adults through an Understanding of the Learning Needs of Individuals  
Who Have Personally Experienced Delirium  
– Final Report

# Collaborative Research Grant Initiative: Mental Wellness in Seniors and Persons with Disabilities

## Final Report - Promoting Early Identification and Prevention of Delirium in at Risk Older Adults through an Understanding of the Learning Needs of Individuals Who Have Personally Experienced Delirium

### EXECUTIVE SUMMARY

This project was aimed at improving early recognition and prevention of delirium by strengthening older adult and family members' awareness and understanding of this serious health concern. Although delirium is one of the most common older adult conditions encountered in health care, it remains among the least recognized and understood. There is compelling evidence that reducing delirium occurrence and its adverse effects contributes to both quality of life and health care savings.

Through a semi-structured interview process, ten volunteers shared their stories of either experiencing delirium or being present during the experience of an older family member.

Four overarching themes emerged from the interviews:

- Theme I: Memories of the Delusions;
- Theme II: Expressed Desire for Stronger Connectedness with Health Care Providers;
- Theme III: Perceived Need for Enhanced Delirium Care; and
- Theme IV: Self Perceived Knowledge Deficit.

Recommendations for delirium information content, format, and dissemination strategies were made by the participants.

Project findings are markedly consistent with the findings of numerous studies related to both the nature of the delirium experience and the professional practice obstacles to prevention and management of it. These findings have implications for health care provider education, best practice policy, and older adult/family education.

This project reflects a person-centered, collaborative approach to collecting information about delirium. It is suggested that older adults and their family members can be empowered by information to play a key role in prevention or early detection.

## RESEARCH OVERVIEW

### Objective(s)

This project was aimed at improving delirium prevention by strengthening public awareness and understanding. Objectives of the project include:

- i) to gain an understanding of both the delirium experience and delirium-related learning needs of older adults and/or their family members.
- ii) to clarify content, formats and dissemination strategies for delirium-related public education from the perspective of older adults and family members (see Appendix A).

### Background

#### ***Addressing the Problem: Delirium in the Older Adult Population***

Delirium is an acute confusional state. It is a common, life threatening, and potentially preventable adverse event among individuals 65 years of age or older (Inouye, 2006). It develops quickly over a few hours or days. A key feature includes a sudden change in awareness and attention. Thinking may become disorganized and speech may be rambling. The person may be unusually agitated or sleepy and withdrawn (Featherstone, Hopton & Siddiqi, 2010).

Delirium is rarely caused by a single factor. It is a multi-factorial condition, which involves a complex relationship between predisposing and precipitating factors (Alagiakrishnan, Marrie, Rolfson & Coke, 2009; Mittal, Williamson, Thomas & Tampi, 2011). Predisposing factors increase an older adult's vulnerability for developing delirium. They include: older age, pre-existing cognition change, impairments of vision and hearing, physical frailty, history of depression, dehydration, presence of multiple medical conditions, and severe illness (Canadian Coalition for Seniors' Mental Health, 2006; Sendelbach & Guthrie, 2009). For people with strong vulnerability, fewer or less severe precipitating factors (triggers) are required to cause an episode of delirium. Triggers of delirium are diverse and can include: acute illness (such as infection, congestive heart failure, or electrolyte imbalance), medications, surgery, lack of sleep, immobility, constipation, change in familiar place of residence and/or routine, and presence of medical devices (restraints, bladder catheters).

Reported rates of delirium are highest among acute hospitalized older adults. Inouye (2006) cited a 14-24% prevalence at time of hospital admission and a 6-56% incidence during hospitalization. Among specialized populations, the incidence of delirium is even higher: 25-65% of patients with hip fractures, 74% among surgical patients, and 11-42% among general medical in-patients (Holroyd-Leduc, Khandwala & Sink, 2009). The high prevalence of delirium at admission suggests delirium develops before hospitalization and may be a primary factor resulting in hospitalization (Bond, 2009; Fong, Tulebaev & Inouye, 2009). According to Inouye (2006), delirium occurs in up to 60% of patients in nursing homes or post-acute settings. Prevalence of delirium in persons with dementia ranges from 22-89% in both hospital and community settings (Fick & Kolanowski, 2009). The large variation in reported rates is likely due to sample characteristics such as age, method of case finding and variations in diagnostic criteria.

#### ***Importance of Addressing the Problem: Consequences of Delirium, Delirium Prevention, and Family Involvement***

Delirium is considered a medical emergency that needs to be treated quickly (Canadian Coalition for Seniors Mental Health, 2006; Fong et al., 2009). Patients who develop delirium have significantly worse outcomes than those who do not develop it. Delirium is associated with increased morbidity and mortality, increased cost of care, longer hospital stays, increased hospital acquired complications, poor functional and cognitive recovery, and increased rates of discharge to long term care facilities (Holroyd-Leduc et al., 2009; Mittal et al., 2011). Older adults' descriptions of their delirium episode reveal a frightening experience of hallucinations, delusions, paranoia, and loss of control.

Clinical trials provide compelling evidence that at least 30 to 40% of delirium cases may be preventable (Mittal et al., 2011). Since delirium has numerous causes, multi-component preventive approaches targeted at modifiable risk factors are considered the most effective strategy for reducing its occurrence and adverse outcomes. The challenges to delirium prevention, however, are significant. Although delirium is one of the most common older adult conditions encountered by health care providers, it remains among the least recognized and understood. Factors contributing to the lack of early recognition, diagnosis and therefore prevention include a lack of delirium education among health care providers, failure to determine functional and mental status baseline information for ill older adults, lack of formal cognitive assessment, misdiagnosing delirium as dementia or depression, and lack of appreciation of the consequences of delirium (Tabet, Hudson, Sweeney & Howard, 2005; Inouye, 2006; Mittal et al, 2011).

As stated in the Canadian National Guideline document, lack of knowledge is a fundamental but modifiable obstacle to delirium prevention (Canadian Coalition for Seniors' Mental Health, 2006). Recommended approaches to improving knowledge are aimed not only at health care providers but also older persons, their families and other informal caregivers. It is acknowledged that informed family can play a key role in the detection, prevention, and management of delirium in older persons. Studies have indicated that patient information can improve patient outcomes (Sadowski, 2011).

## **Approach and Methods**

### ***Literature Search***

A review of the literature was conducted through a search of CINAHL, Medline, PubMed, ERIC, Psyc INFO, Sociological Abstracts, Embase, and AMED. A combination of search terms related to the personal experience of delirium, delirium public education, public information resources, and family's role in delirium prevention were used.

Numerous studies have focused on the delirium experience of adults with advanced cancer and on the delusional experiences of patients in Intensive Care settings (Misak, 2004; Price, 2004; Ringdal, Johannson, & Lundberg, 2006; Storli, Lidseth & Asplund, 2008). Only two studies (hospital setting) reported on the delirium experience of older adults (McCurren & Cronin, 2003; Duppils & Wikblad, 2007). Current available evidence on delirium prevention and education is directed primarily at hospital settings, health care staff and physicians. Keyser's thesis work (2010) is reported as the first known study on a delirium educational intervention specifically targeting older adult families outside of the hospital setting. One study in a hospital setting demonstrated that active engagement of family care givers in preventive interventions is feasible (Rosenbloom-Brunton, Henneman & Inouye, 2010).

### ***Environmental Scan***

A scan of delirium-related public information resources currently in use by local and provincial health services, seniors' community programs, and seniors' organizations was completed. A preliminary review at a national level was also done. The scan revealed limited public information resources in use (see Appendix B).

### ***Interviews***

Project volunteers were recruited through poster dissemination to several service sites/community dwellings. A letter was also sent to geriatric specialty clinicians requesting recruitment assistance (Appendices C, D, and E). Ten persons volunteered. Volunteers included four older adults who experienced delirium during an acute illness and six family members who were present during the delirium episode of a spouse or parent (two spouses, three daughters, one son). Information about the project and use of the interview data was provided (Appendix F). Consent for interview audio taping and data transcription was obtained.

The nature of the delirium experience and related learning needs were explored through semi-structured interviews (Appendix G). During the recruitment process, volunteer contact with the research assistant was sporadic; therefore, individual interviews were arranged at the time of contact. The duration of each interview session was 1 1/2 to 2 hours. Participants were eager to talk about their experiences. It is

possible that “one to one” interviews allowed for more comfortable sharing of details than might have occurred in focus group settings that were initially intended.

## **Key Findings**

It was primarily through the interviews that the following four overarching themes about the delirium experience and participant learning needs emerged:

Theme I: Memories of the Delusions;

Theme II: Expressed Desire for Stronger Connectedness with Health Care Providers;

Theme III: Perceived Need for Enhanced Delirium Care; and

Theme IV: Self Perceived Knowledge Deficit.

### ***Theme I: Memories of the Delusions***

Memories of the delusions were central to the delirium experience. Delusions were described in three ways: the realness of the delusional events, the persistence of delusional memories over time, and the emotional depth of delusional events.

The perception of how real the delusions seemed to be was commonly and repeatedly expressed. It seemed that even though participants could verbalize the illogical nature of a delusional memory, they found it hard at the same time to believe it didn't happen because the experience seemed so real.

Participants offered information about strategies that helped:

seeking reassurance from supportive others in clarifying the real from the unreal memories;  
family presence;

learning that delirium is not uncommon and does clear, and being treated with compassion;  
being able to talk about lingering memories with trusted persons.

Post delirium follow up sessions were suggested by participants as possible strategies. Three of four former patients who experienced follow up programs (either Day Hospital or Geriatric Assessment & Rehabilitation) expressed gratitude for these programs. When the delusional thoughts were perceived as dismissed or made light of by others, participants expressed feeling troubled. They became guarded about what they said and to whom.

Although not all delirium experiences are remembered (Ringdal et al, 2006), participants in this project indicated that when experiences are remembered, in particular delusional experiences, the memories are long lasting. They continue on well beyond discharge from hospital.

Strong emotion experienced from delusional events was a predominant theme. Emotions seemed more intense in the shorter term (3 months post hospitalization) and less intense in the longer term (2 years and 53 years afterwards), although all events were vividly remembered. For participants in this project, intense emotions arose: fear of not feeling safe; a feeling of loss of control; fear of dying; and distress from the struggle of sorting out the real from imagined memories. The post delusional impacts on quality of life were reported as sleep disruption, persistent “horrible” nightmares about loss and dying, ongoing “terrifying” feelings about a “near miss” experience, lingering concern about the possibility of mental illness and social withdrawal.

One participant's delusion involved her brother who she believed was admitted to the same unit and died:

“It went on each day. It was so real. I found a big room....the former solarium. I thought my sister and cousin were holding a coffee party for the people who had come to see my brother. I was sure I could hear his horses outside. Some nights I was afraid to fall asleep because I knew I would hear my brother or believe he was dead. My son reassures me it wasn't real.”

When asked what the most difficult part of the experience was for her, this participant (3 months post hospitalization) responded:

“The realness, the horribleness of the experience: the fright. I can’t get it out of my head totally. I still get nightmares that are terrible, always about people dying and things in my past that were not happy. I’ve dreamt we were out camping and a bear got my son.”

### ***Theme II: Expressed Desire for Stronger Connectedness with Health Care Providers***

Participants expressed an unmet desire for attentive responses to their concerns and questions by health care providers. Family members expressed vulnerability in their efforts toward advocating for their loved ones. They described feeling isolated, dismissed, annoyed, a sense of chaos, and frightening uncertainty. Health care provider responses such as acknowledging and exploring concerns, taking time to answer questions and involving family members in the care of their loved one were described as necessary for a stronger sense of feeling connected.

One stated:

“I didn’t expect the nurse to go into detail but just some acknowledgement that there was something not right going on. I felt dismissed by nurses and physicians.”

In the following case, the medications were changed in such a way as to contribute to the delirium. A daughter explained that she was not consulted about changes to her mother’s medication regimen even though she knew the total picture of her mother’s chronic illness management at home. She said:

“Families need a bigger voice. Some medications should not be changed!”

### ***Theme III: Perceived Need for Enhanced Delirium Care***

Participants described what they perceived as gaps in health care professional knowledge and delirium care. They described numerous failed attempts to obtain satisfactory explanations from health care providers regarding experienced changes in mentation and behaviour. Delirium was not presented as a diagnosis or possible post-operative complication. Information about baseline cognitive and physical functional ability of the older adult patient with delirium was not sought from family members. Responses to the interview question of what advice participants would give to professionals caring for the person with delirium generated numerous suggestions (Appendix H). A question arises from the findings as to whether delirium care is complicated by an ageist mindset among health care providers. Findings suggest that a possible barrier to skilled care may be a perception among health care providers that confusion is normal among ill older people.

Interventions identified as best practice in the literature were implemented by family members themselves. One participant said:

“The most comforting thing was that my sister and I took turns caring for Mom in hospital and were able to be there for her. We read the newspaper, re-oriented her, and talked about news from the PAL (her residence) and her friends.”

### ***Theme IV: Self Perceived Knowledge Deficit***

Participants recognized a need for knowledge of delirium. They described the experience of not having information as difficult, annoying, frightening and contributing to chaos. During the delirium experience participants obtained information from friends who had been through a similar experience, from the internet or from a friend in the health care profession with knowledge of geriatric care. Delirium information desired by the participants was clarified (see Appendix I).

## **Conclusions**

The findings of this project are markedly consistent with the findings of numerous studies related to both the nature of the delirium experience and the professional practice obstacles to prevention and management. The following are summary statements of the conclusions of this project:

Participants’ recollections of their delusional experiences reveal a frightening world of misinterpretations and loss of control. Emotional distress from a delirium experience can persist

beyond hospitalization and complicate recovery. The intensity of the delirium experience and its consequences for both patient and family tend not to be acknowledged by health care professionals.

There was a perceived need for delirium-related education and improved care skills for health care providers. Perceived knowledge gaps relate to delirium risk factors, symptoms, and assessment. Skilled delirium care requires caring sensitivity to the confused older adult who is feeling threatened, unsafe and insecure. A related complicating factor to skilled care may be the stereotyping of older adult patients as being normally confused.

Patients and family members want to play a key role in the prevention and management of delirium. Their expressed desire for involvement includes: having information for early identification, knowing how to work with the person who is showing early signs of delirium and participating in delirium care with health care providers.

A family centered model of care is desired. In this project, family centered care approaches of exploring concerns, answering questions and inviting family involvement in care are viewed as paramount to promoting patient/family satisfaction and control.

Improving public awareness of delirium was supported by the participants. Participant suggestions for information content, format and dissemination strategies are provided in Appendix I. Clarifying what older adult members and their caregivers want to know about delirium and how they would best access this information is consistent with a person centered, collaborative approach to providing public information.

Appendix J contains significant quotes about the delirium experience.

## **IMPLICATIONS FOR POLICY OR PRACTICE**

### ***Health Care Provider Education***

The need for delirium education among health care providers is well documented. Recent studies demonstrate a significant benefit to delirium prevention and management when an interdisciplinary approach to education is used (Teodorczuk, 2009). Educational programs should emphasize the emotional impact of the delirium experience for both patients and family members. Using narrative excerpts as an educational strategy may assist in heightening health care provider appreciation of the frightening, threatening reality of the delirium experience and its consequences.

### ***Best Practice Guidelines***

The findings of this project and their congruence with research findings draw attention to a knowledge translation challenge. There is a gap between what best practice evidence is urging for delirium prevention and management and what is reported as happening in practice. There is a need to take a more organized, aggressive approach to prevention. Besdine and Wetle (2010) described delirium as a substantial missed opportunity for health promotion/disease prevention among older adults. Relying on late detection and treatment of delirium is contrary to compelling evidence that at least 30 to 40% of cases may be preventable. Integrating a delirium screening strategy into practice guidelines is recommended. Evidence based practice protocols should be implemented for older adults found to be at risk. Standards of delirium care should be recognized as required clinical competencies for acutely ill older adults.

### ***Older Adult/Family Education***

Older adults and family caregivers can be empowered through information to play a key role in delirium prevention. Delirium prevention activity can begin in the home setting through early identification of subtle cognitive and functional changes, seeking rapid treatment and promoting optimal wellness. For example, maintaining the use of visual and hearing aids, maintaining hydration, and promoting sleep are recognized as strategies to prevent delirium. As recommended by project participants, numerous

community sites/programs can serve as access points for public information about delirium. The preferred format for receiving information is a combination of written and verbal presentation (Appendix I).

### ***A Family Centered Care Approach***

A family centered approach is urged in the care of at risk older adults. A family centered care model fosters active participation in care giving and decision making (Wright & Leahey, 2009). This model is appropriate for ill older adults with delirium who are dependent on the decision making input and support of family members who know them well. As one participant expressed, "Illness is a family event. For the older person and their spouse, the illness can be a major life altering transition."

## **DIRECTIONS FOR FURTHER RESEARCH**

- Implement a delirium related public information campaign based on project based recommendations for content, format and dissemination approaches;
- Explore the need for and benefits of post acute delirium follow up care (e.g. debriefing sessions, psychotherapy);
- Explore learning needs and delirium care experiences from the perspective of health care professionals and
- Re-examine project interview data for additional research questions related to delirium.

## **KNOWLEDGE DISSEMINATION AND TRANSLATION ACTIVITIES**

The following strategies are suggested:

- formal report to Alberta Health Services (provided);
- journal article / or newsletter item;
- sharing of project results with service providers and community representatives with approval of AHS; and
- distribution of findings to students and educators through the Brenda Strafford Centre for Excellence in Gerontological Nursing.

## PRINCIPAL APPLICANT (TEAM LEADER)

Please list team leader, his/her position title and areas of interests.

Name	Position Title	Topics of interest
<b>Mollie Cole, RN, MN, CGN (C)</b>	<b>Lead, Specialized Geriatric Services, Alberta Health Services</b>	<b>Gerontological nursing and interprofessional practice: Cognitive Impairments – dementia and delirium</b>

## PROJECT PARTNERS (TEAM MEMBERS)

Please list all other project partners, their position titles (including organization) and project roles.

Name	Position Title	Role
<b>Sandra P. Hirst RN, PhD, GNC(C)</b>	Associate Professor  Director, Brenda Strafford Centre for Excellence in Gerontological Nursing	Project role (i.e., data analysis and data synthesis, report editing, process advisement, admin resources 'in kind')
<b>Margaret Heinkel Wylie, RN, MN</b>	Research Associate	Literature review, participant data collection, data analysis, data synthesis, final report writing.

## FUNDING

No external funding was used for this project.

## PUBLICATIONS AND PRESENTATIONS

Presentation on the findings planned for a January 19, 2012 Gero Nursing Rounds in Calgary.

## **ABOUT THE ALBERTA ADDICTION AND MENTAL HEALTH RESEARCH PARTNERSHIP PROGRAM**

The *Alberta Addiction and Mental Health Research Partnership Program* is comprised of a broad-based multi-sectoral group, representing service providers, academic researchers, policy-makers and consumer groups, working together to improve the coordination and implementation of practice-based addiction and mental health research in Alberta.

The mission of the Research Partnership Program is to improve addiction and mental health outcomes for Albertans along identified research priority themes, by generating evidence and expediting its transfer into addiction and mental health promotion, prevention of mental illness, and innovative service delivery.

The Research Partnership Program sets out to increase Alberta's excellence and output of addiction and mental health research findings, and to better translate of these findings into practice improvements.

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## Appendix A

### Specific Description of Project Objectives

The objectives are to:

1. Conduct an environmental scan of delirium information resources currently in use at the community level.
2. Conduct a literature review of current evidence related to resources and strategies for delirium prevention.
3. Conduct focus group discussions to understand delirium from the perspective of older adults who have had the experience and/or family members who have been present during that experience.
4. Explore learning needs in discussion with older adults and/or family caregivers who have had a delirium experience to:
  - i. determine what information was or could be helpful in facilitating early recognition of delirium.
  - ii. determine what information could be helpful in preventing or mitigating delirium.
  - iii. determine actual and recommended information sources, formats and dissemination strategies for increasing public knowledge of delirium.
5. Strengthen delirium prevention activity at local community and provincial levels in Alberta through recommendations for enhancing the relevance and dissemination of delirium information materials.

## Appendix B

### Environmental Scan of Delirium-related Public Education Resources

SERVICE/PROGRAM	PUBLIC EDUCATION RESOURCES
Alzheimer Society of Calgary Dementia Care Training	Three levels of education within the program: <ul style="list-style-type: none"> <li>• general public education sessions</li> <li>• family caregiver centered (individual support &amp; workshops)</li> <li>• staff training</li> </ul> In public education sessions, touch on delirium when discussing the 3 D's ( delirium, dementia & depression) Recent publication to be made available to the public: Canadian Coalition for Seniors' Mental health.
Alzheimer Society of Calgary Family Support	Delirium is touched upon, not in depth, in small community workshops, community information forums (3x/year). In family support workshops (1x/month), the 3 D's are expanded upon to assist families in distinguishing them. "Occasional light bulbs go on for those having had the experience of delirium."
Alzheimer Society of Alberta & Northwest Territories	No information forwarded.
Calgary West Central Primary Care Network	No delirium education resources for the public. Education is for staff in form of CMEs (physicians & Allied health) and monthly sessions for Allied Health. Expressed interest in having presentation on delirium from this project team. Manager & team leader of nursing are exploring delirium best practice guidelines & full scope of practice for their organization. (reference for Coalition booklet & pocket care sent to contact person)
Calgary West Central Primary Care Network Medical Inpatient Services	No materials on delirium for the public. One to one conversations where applicable.
Calgary Foothills Primary Care Network	Not aware of delirium materials for the public.
Calgary Emergency Departments FMC, RGH, PLC	No public education materials in use.
Family Physicians' Association of Calgary	Seniors' Leader not aware of whether any or how much delirium information available. Would like to assist with the roll out of materials being promoted by this project.

SERVICE/PROGRAM	PUBLIC EDUCATION RESOURCES
<p>Doctors' Offices:</p> <p>Southcentre Family Practice</p> <p>Eaglesmed Walk in Clinic</p> <p>Crowfoot Village Family Practice</p> <p>Orthopedic Surgeon's Office Family Practice Northwest</p>	<p>No delirium materials. Pamphlets on planned pregnancy/parenthood, osteoporosis, cervical cancer, smoking cessation, Seniors' Plus Blue Cross plan.</p> <p>No materials on delirium.</p> <p>No materials on delirium</p> <p>No materials on delirium.</p>
Kerby Centre, Calgary	Not aware of delirium related resources within the centre.
Geriatric Mental Health Team: Sheldon Chumir Centre	No materials for the public. On a regular basis, Staff will access information on the internet for specific patients. Education on delirium is staff focused. The team provides consultation & education to care centres in relation to elderly residents with mental health concerns.
Health Link	No brochures. No reference to delirium in healthlinkalberta.ca BC references will soon be available by a link on the website.
Supportive & Family Living, Calgary	No public information materials. Recent education session for professional staff and nursing attendants.
Chronic Pain Services	No public resources on delirium.
Day Hospital Program, Calgary	One to one discussion with patients/family members with diagnosis.
Alberta Council on Aging	No known dissemination of delirium education resources from this service.
Confederation Park Senior Citizens' Centre, Calgary	No materials on delirium.
Shoppers Drugstore Northland Mall, Calgary	No materials on delirium.
Shaganappi Co-op, Calgary	No resources on delirium.
Dalhousie Safeway, Calgary	No resources on delirium.
Surgery Pre-admission clinic	Information provided for elective orthopedic surgeries (includes section on delirium)
Alberta Health Services	Availability of information booklet through patient education Delirium: Information for Patients & Families. Websites provided in booklet for additional information

SERVICE/PROGRAM	PUBLIC EDUCATION RESOURCES
Canadian Coalition for Seniors' Mental Health	2011 information booklet available: <a href="http://www.ccsmh.ca">www.ccsmh.ca</a>
Vancouver Island Health Authority	Provide: Public information booklet on delirium Information poster & video presentation <a href="http://www.viha.ca/mhas/resources/delirium/family_guide.htm">http://www.viha.ca/mhas/resources/delirium/family_guide.htm</a>
Regional Geriatric Program Hamilton, Ontario	Public information poster available

Appendix C (Volunteer Recruitment Poster)

Alberta Health Services and the Brenda Strafford Centre for  
Excellence in Gerontological Nursing  
Quality Improvement Project to Promote:

# Public Awareness of Delirium

## *Delirium is:*

- *a state of confusion that develops quickly and can be frightening*
- *usually caused by illness or medication reaction*
- *usually temporary*
- *often preventable*

Have you (or your family member) experienced  
delirium in illness?

Would you be willing to  
share your story of that experience?

The goals of this project are to:

.... gain understanding of the patient/family perspective, and to

.....determine what information about delirium would be helpful

*To volunteer and/or for more information please phone the Brenda  
Strafford Centre for Excellence in Gerontological Nursing, University of  
Calgary:*

**403 220-5960 (Lisa)**



**Deadline for Volunteering is June 20, 2011**



## Appendix D

### Recruitment Poster Dissemination Sites

Thirdagecommons.com website

Alzheimer Society Website (175 links to service providers)

Whitehorn Retirement Residence

Primary Care Network- Foothills

Carewest Day Hospital North and South

Carewest Sarcee

Clinical Nurse Specialists Geriatric Services, Calgary zone, AHS

Geriatricians, Calgary zone, AHS

Nurse Practitioners: Integrated Supportive and Facility Living, Calgary zone, AHS

Education Consultant ISFL Calgary (site contacts in Continuing Care and DAL including physicians)

Wentworth Manor

Confederation Park Seniors' Centre

Kerby centre

Cambrian Manor

Chinese Caregiver Support Group and Seniors' Association

Alberta Seniors' Association

Bridgeland Clinic

**Appendix E**  
Letter to Geriatric Clinicians

To: Geriatricians and Seniors' Health Clinicians

**Re: We are seeking your assistance in recruiting participants for a quality improvement project related to delirium and public awareness.**

**Project Title**

*Understanding the Experience of Delirium From the Older Patient and Family Caregiver Perspective to Help Determine Learning Needs.*

**Sponsorship**

Sponsorship is through a Collaborative Initiative Grant and is supported by: Mental Health Screening and Early Identification; Brenda Strafford Centre for Excellence in Gerontological Nursing, U of Calgary; Specialized Geriatric Services, AHS

**Project Purpose**

To

1. gain an understanding of public information/education needs related to early recognition and prevention of delirium in the older adult population,
2. develop education strategies (formats and key messages) for improving public knowledge.

**Approach**

Focus group discussions will be used to gather experiential information. The aim is a minimum of 16 participants divided among a number of focus groups.

**Participant inclusion criteria**

1. voluntary participation
2. older adults who have experienced delirium 3 or more months ago
3. a supportive family member of an older adult who has had delirium.

**Specific help requested from geriatricians and clinicians:**

We would very much appreciate your help in:

1. identifying potential participants with a recent diagnosis of delirium (3 or more months ago)
2. providing potential participants with a poster (attached) that advertises the project and clarifies a contact number for volunteering.

## Appendix F

### Volunteer Information Page (1)



#### **Purpose of Project**

The purpose is to:

- gain an understanding of public education needs related to early recognition and prevention of delirium in older adults. In this project, an understanding of education needs will be enhanced by seeking the stories of older adults and family members who have experienced delirium.
- develop education strategies for improving public knowledge.

#### **Sponsorship**

This project is collaboratively sponsored by:

Alberta Health Services Seniors' Health

Mental Health Screening and Early Identification Department

The Brenda Strafford Centre for Excellence in Gerontological Nursing, University of Calgary.

#### **Selection of Participants**

Participation is voluntary.

Eligible volunteers include:

- older adults who have experienced delirium three or more months ago.
- a supporting family member of someone who has had delirium.

#### **Volunteer Involvement**

Volunteers will be asked to:

- attend a two hour interview session in a small group setting (2 to 4 volunteers, the project assistant and a recorder)
- share their story of the delirium experience.
- clarify what information was or would have been helpful for their delirium experience.
- observe displayed education materials and comment on format, information gaps, strengths as well as helpful ways to disseminate the information to the public.

## Volunteer Information Page (2)

### **Confidentiality**

Names of all volunteers will be kept confidential.

The information gathered will not be used in any manner that identifies individuals.

Once the group sessions have been completed, all information will be reviewed to identify themes related to public knowledge strengths and gaps. Themes related to delirium care gaps and strengths may also be evident.

Volunteering implies permission to:

- record and audiotape interview information for the accurate identification of themes.
- use the information in aggregate form, that is, sharing of themes for the purpose of educating others and improving delirium care.

Quotes used in the final report will not contain identifying features of individuals or described situations.

Information collected by note taking and/or audio taping will be destroyed within one year of report completion. Until then the information will be kept in a secure location.

Absolute confidentiality cannot be ensured where group size is 4 participants, however, participants will be asked to keep all responses in confidence.

### **Use of Project Information**

Potential outcomes of project include:

- early recognition and prevention of delirium in the older adult population.
- improved management of delirium by health care professionals in partnership with patients and family members.

### **Location/Time**

Focus groups will be held at a time that is convenient. Location will be clarified by telephone.

### **Reimbursement and Support**

Parking fee will be reimbursed at the time of the focus group session.

Sitter support will be provided on location as necessary for older family members with dementia.

A ten dollar coffee gift card will be provided in appreciation to each volunteer.

### **Contact Information**

For additional information, contact the Brenda Strafford Centre for Excellence in Gerontological Nursing, University of Calgary, 403-220-5960.

## Appendix G

### Semi-structured Interview Questions

#### **The Delirium Experience**

What was the experience?

At the time, what did you think was happening?

What was the experience like for you?

What was the response of those around you to this experience?

What did you do to seek help?

Did you communicate this experience to anyone and what was the response?

What was the most difficult thing about the experience?

What was the most comforting thing about the experience?

What kind of help were you able to obtain? (where and from whom: supports and services within and outside of AHS?)

Who gave you the diagnosis of delirium?

How long did it take to recover?

Would you have benefited by staying in hospital longer than you did? What help/care was required at home?

In what way could the experience have been better managed within the health care system?

What would you like health care professionals to know about caring for someone experiencing delirium?

#### **Delirium Information Needs**

What did you know about delirium prior to this experience?

What information would have been helpful to know prior to this episode?

Where /from whom did you seek out information during this experience?

What information/assistance provided by health care professionals was helpful during your experience?

What was missing in the information you were able to access? In the discharge info?

What information about delirium do you wish to know now?

How would you currently prefer to receive information about delirium?

Format: brochure/pamphlets, internet, videos, articles, verbal presentations, posters  
(comment on samples)

Source: newspaper, seniors' publications, library, seniors organizations, hospital,  
doctor's office,

community programs, personnel, other sources.

Dissemination strategies: newspaper, internet, mail, presentations/speakers, other.

Where/from whom might the educational material have been provided prior to the event to help prepare for the possible occurrence of delirium?

What question have I not asked that I should have asked?

## Appendix H

### Participant Suggestions for Enhanced Delirium Care

- use a delirium assessment approach on admission and ongoing, particularly one that will expose the depth of the illogical thinking.
- explain delirium, the symptoms, the course, it's reversibility and expected outcomes.
- Provide advice on how to talk with the person who has delirium.
- provide explanations before giving care.
- reassure (often) the delirious person that he/she is safe.
- use bed rails judiciously for the person with delirium.
- Do not do anything that will startle the person who has delirium.
- be gentle in care approach.
- offer a review of the hospital course to those who have experienced delusions.
- improve staff continuity.
- start with the lowest dosages of medications.
- be open to referring to specialties that can help with understanding the total picture.
- inform the family physician about the delirium experience.
- recognize that severe illness and delirium are frightening for patients and families.
- know that illness is a family event and all members are affected. For the older adult and their spouse, the illness can be a major life altering transition.

## Appendix I

### Participant Recommendations for Delirium-related Information

Content	Format	Dissemination
<ul style="list-style-type: none"> <li>• what delirium is</li> <li>• that delirium can happen</li> <li>• that delirium can be a post-operative complication</li> <li>• that delirium is not uncommon in ill older people</li> <li>• that a person can clear from it</li> <li>• that delirium is different from dementia (and how)</li> <li>• early signs to know delirium is starting</li> <li>• what causes delirium</li> <li>• how to prevent it</li> <li>• how to get help</li> <li>• what to do to work with it (ie proactive interventions like orientating, not arguing with the confused person)</li> <li>• how to talk with the person who is confused</li> </ul>	<ul style="list-style-type: none"> <li>• a combination of verbal &amp; written information is a preferred format because:               <ul style="list-style-type: none"> <li>• verbal information would draw more attention initially.</li> <li>• older adult is not a great reader (x3 participants).</li> </ul> </li> <li>• a public talk with written information to take home is good for reinforcement.</li> <li>• pamphlets</li> <li>• publications.</li> <li>• video presentations 8 to 10 minutes long, then a question &amp; answer session</li> <li>• challenge is to attract attention to the word delirium. People don't know delirium or how common it is. People know dementia. Most people don't get curious about something they haven't experienced.</li> <li>• need a title that grabs attention. eg <i>Delirium Is Not Dementia!</i></li> <li>• posters that are bright in color so they stand out, catchy phrases, columns, not too much detail.</li> <li>• Perhaps someone (where seniors gather) could read the information to the group, then send written information home with people.</li> <li>• It is important to include involved family members in providing information.</li> <li>• Alberta Health Services and CCSMH booklets were perceived as good information resources.</li> </ul>	<ul style="list-style-type: none"> <li>• Information into doctors' offices is essential (all participants).</li> <li>• emergency departments, units with elderly patients, hospital hallways, patient rooms.</li> <li>• discharge information - what patients can expect post acute phase in the days, weeks, months to follow.</li> <li>• health clinics, Sheldon Chumir, day programs.</li> <li>• Primary Care Networks, Health Link</li> <li>• should be provided in pre-operative sessions and part of a pre-operative package.</li> <li>• seniors' services like Alzheimer Assoc'n, Kerby Centre</li> <li>• seniors' groups/clubs, community centres where seniors gather for coffee.</li> <li>• seniors' residences like PAL, DAL, Horizon Village, Lodges, Statesman has 4-5 buildings.</li> <li>• Safeway and other pharmacies</li> <li>• victim assistance units through the Calgary Police Service (hold seniors' sessions)</li> <li>• Seek sponsors for a delirium awareness day (like diabetes day)</li> <li>• door to door campaign with brochures &amp; quick introduction</li> <li>• blitz like heart &amp; stroke month using TV, radio</li> <li>• health report channel (CTV, Shaw cable channel)</li> <li>• Calgary Herald insertion</li> <li>• AHS mailout to senior populations of laminated cards with key points</li> <li>• finding people in the seniors' community who are able to bring the message---along the line of community watch. They can continue to be updated through access points. (train the trainer idea)</li> <li>• seniors' websites</li> <li>• Seniors' groups are often looking for speakers for presentations.</li> </ul>

## Appendix J

### Additional Narrative Excerpts of the Delirium Experience (1)

One participant was very ill with an infection and described driving her car to an appointment.

“I couldn’t figure out why I wasn’t crashing. I was hitting other cars or the side of the curb. I realize now I probably wasn’t. I couldn’t believe that someone didn’t yell because I thought I hit their car sideways like a bump. I had been completely aware that it was not possible but I thought it was happening. I told my grandson and he said that if I was bumping into cars they would have pulled me over somewhere.”

One participant was eager to tell her delirium story even though her experience happened at age 15. She said, “What is so characteristic for my event is that now when I am almost 70, I remember it like it was yesterday”

One participant at 3 months post hospitalization was still bothered by intrusive delusional memories of a dead brother. “I still to this day believe I saw M. (her brother) lying there in the next room.”

A participant who is 2 years post hospitalization described in detail his delusional experience of being in a Tibetan hospital and fear of being harm.

One participant (3 months post discharge) talked about being horrified by the possibility she might have done something to jeopardize her safety or the safety of others, especially while driving to an appointment. She said,

“The first one (delirium episode) put the fear of God into me! The fear is actually worse after the fact because you realize what might have happened. Something had taken over me that I had no control over. That’s a terrible feeling.” She referred to her delirium experience as a “near miss”. She expressed concern about being viewed by others as “being crazy” due to the delirium experience.

“The most difficult thing was seeing mom look like a drunk -- no coordination, steering her spoon past her mouth and over her shoulder on the opposite side. That unsettled me!” When this participant tried to explain her mom’s change in behaviour to the physician, her concern was not addressed. She said, “He looked right past me!”

Commenting on what was difficult for her about the delirium experience one participant said, “On the unit the nurse was in total denial of what we were trying to ask about, feeling like we were not getting any answers. If she could have just said it looks like delirium, sometimes after surgery older patients experience this, it is not typically permanent, here is some information.”

One participant described her effort to seek information about delirium. She said “When I mentioned it they blew me off. I felt like an inconvenience.”

A daughter described the most difficult aspect of the delirium experience

“Just the lack of information, not knowing what to do and what the options were and where mom would be going. We had to research things ourselves.”

In relation to one patient who slept excessively (a sign of hypoactive delirium) the daughter said, “They need to understand normal sleep pattern.”

Other comments:

“When a patient is admitted the cognitive levels should be tested because if all of a sudden you switch, then it’s known as not normal.”

“I went to the nurses and questioned what was going on. They said this happens to 75% of geriatric patients.”

“We knew there was something not right going on. We tried to explain that Dad is not normally like this. Anytime we asked the nurse about what was going on, she would answer with the explanation that he had gone through a serious surgery. Even when we spoke to the doctors they would explain it away because of multiple surgeries.”

“I brought in pictures so when she (Mom) started to drift I would pull out the pictures and remind her that her mother was gone and try to steer her clear of thinking her mother was still alive. I tried to gently bring her back, to guide her to the present.”

“I was annoyed there was no warning for the family. It would have been nice to have been told (at the outset) of the possibility of this happening.”

One participant whose mother was the patient, described her dad as heart-broken. “He was in denial, not grasping that mom was not coming directly home but going to a convalescent unit for a period of time. He didn’t know how to be there for mom because he couldn’t be there for himself.”