



Knowledge Network in Rural and Remote Dementia Care

Healthcare Delivery across the Continuum for Rural and Remote Seniors with Dementia

Third Annual Summit - October 28th and 29th, 2010 Saskatoon

Final Report





Save the Date

Mark your calendars now
for the 4th Annual Knowledge
Network in Rural and Remote
Dementia Care Summit

October 27th & 28th 2011
Saskatoon

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Welcome

Dear Knowledge Network Members,

Thank-you to everyone who participated in this year's Summit, the knowledge-exchange event attended by members of the *Knowledge Network in Rural and Remote Dementia Care*. This was the 3rd Summit to be held in conjunction with the CIHR-SHRF Applied Chair in Health Services and Policy Research that I hold. The Chair research program is titled *Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia*.

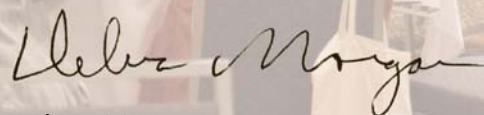
The Summit brings together the Decision-Maker Advisory Council for the Applied Chair program, members of the Chair research team, and other individuals with an interest in the care of persons with dementia in rural and remote settings. Fifty-four people attended this invited event this year, which was held October 28th and 29th in Saskatoon. A number of participants suggested that the Summit should expand to include other stakeholders such as the regional health authorities for example, so that more people can benefit from the exchange of information and ideas for improving health service delivery in rural and remote areas.

I would like to acknowledge the funding support provided by a Canadian Institutes of Health Research (CIHR) Meeting, Planning, and Development grant, and a Knowledge Exchange grant from a CIHR Centre for Research Development project, awarded by the Canadian Centre for Health and Safety in Agriculture (CCHSA).

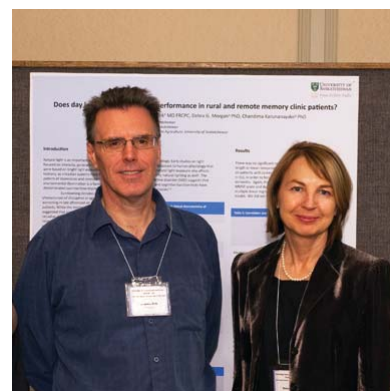
The 4th Summit will be held October 27th and 28th, 2011 in Saskatoon, so please put those dates in your calendar. We are planning an interactive poster session on the evening of Thursday, October 27th and a full day event on Friday, October 28th. Your feedback in the evaluations from this year's Summit are very helpful, and will guide our planning for the 2011 meeting.

On behalf of the research team, I would like to thank you for attending the Summit and helping to guide our research and other activities. I know I speak for everyone when I say how inspiring and invigorating it is to work together with such a knowledgeable group of people who are committed to improving dementia care in rural and remote areas. I look forward to seeing you in 2011.

Sincerely,



Debra Morgan



Introduction

Following the day's agenda on the next page, this report summarizes the activities of the 3rd Annual Summit of the Knowledge Network in Rural and Remote Dementia Care held in Saskatoon on the 28th and 29th of October 2010.

This third meeting of the group was a time for the continued exchange of ideas between invited decision makers, researchers, guests, and friends of the Network. As a part of the activities of the Applied Chair in Health Service and Policy Research Program (funded by the Canadian Institutes of Health Research (CIHR) and the Saskatchewan Health Research Foundation) the Summit provides an opportunity to foster research and knowledge exchange between participants. Attendees included members of the Rural and Remote Dementia Care research team (founded 2003 through a CIHR New Emerging Team grant) and Decision Makers who work 'in the field' to plan and provide care to people affected by dementia, their families, and communities.

Summit activities began on the evening of the 28th with a wine and cheese poster reception. As a prelude to the meetings on the 29th, the evening offered a chance for participants to engage with each other, and to review some new and on-going dementia care research and programs.

The second day began with a welcome from Dr. Morgan, and an overview of the Summit. Dr. John Keady, Professor of Older People's Mental Health Nursing, University of Manchester, provided the keynote address for the day. The rest of the day's activities included moderated panel discussions, presentations about the impact of dementia in both Saskatchewan and England, and small group discussions during which participants had the opportunity to interact with researchers and provide feedback and insights into current research being undertaken here in Saskatchewan.

At the end of the day, participants provided their feedback about the event before leaving to return home. Everyone agreed that this was a good time of year for the group to meet, and the date for next year's Summit was set for October 27th and 28th, 2011.

Page 23 provides information about how to request more information or resources from this year's Summit.



Summit Agenda

Agenda

Knowledge Network in Rural and Remote Dementia Care

3rd Annual Summit

October 28th & 29th

Sheraton Hotel – Saskatoon

Thursday, October 28th - Sheraton Hotel – South & West Rooms

7:00 pm – 10:00 pm Registration, Wine and Cheese Poster session and informal networking. Please join us in the South-West room to review posters which highlight a variety of projects from summit attendees. Appetizers will be served, and a cash bar will be available.

Friday, October 29th - Sheraton Hotel – South & West Rooms

8:00 am - 8:25 am **Registration and Breakfast served in the South/West room**

8:30 am – 9:00 am Intro, welcome, and overview of day

9:00 am – 10:00 am Keynote by Dr. John Keady from the School of Nursing, Midwifery and Social Work at the University of Manchester – Manchester, UK

10:00 am – 10:30 am **Morning Break and Coffee**

10:30 am – 11:30 am Panel Discussion: Aging and Dementia in Aboriginal Communities Panel – a moderated, interactive panel discussion – Panel members include Wendy Hulko – Thompson Rivers University, Shawnda Lanting – University of Saskatchewan, Lesley McBain – First Nations University,

11:30 am – 12:00 Joanne Bracken, Executive Director of the Alzheimer Society of Saskatchewan, will provide a brief overview of the Society's report: Rising Tide: The Impact of Dementia in Saskatchewan. Dr. John Keady will provide his insights and first hand experiences with the roll-out of the national dementia strategy in England. There will then be time for questions and discussion.

Noon to 1:00 pm **Lunch served in the South/West room**

1:00 pm – 2:00 pm Panel Discussion: Frontal Temporal Dementia Caregivers Telehealth Support Group – a moderated, interactive panel discussion with the researchers who support the group, and support group members – Panel members include: Gladys Beisel – support group member, Margaret Crossley – University of Saskatchewan, Donna Dalziel – support group member, Sheri Michell – support group member, Ernie Morgan – support group member, Megan O'Connell – University of Saskatchewan

2:00 pm – 2:15 pm Project overviews of developing research projects being lead by team members:
1) Megan O'Connell: Development of a Telehealth Delivered Exercise intervention
2) Julie Kosteniuk: Dementia Diagnosis and Management: Advancing Strategies to Support Rural and Remote Primary Care Providers
3) Sheena Walls-Ingram: Caring for a family member with dementia: Identifying the support and service needs of rural family caregivers.

2:15 pm – 3:15 pm Participants will have the opportunity to interact with the above project leads to explore the feasibility, quality and relevance of the proposed studies.
A light refreshment will be provided during this session.

3:15 pm - 3:30 pm Wrap-up and evaluation of the 3rd Annual Summit, communication strategies for attendees, and setting the date for the next Summit

3:30 pm **Adjourn – thank you for your participation and have a safe trip home**

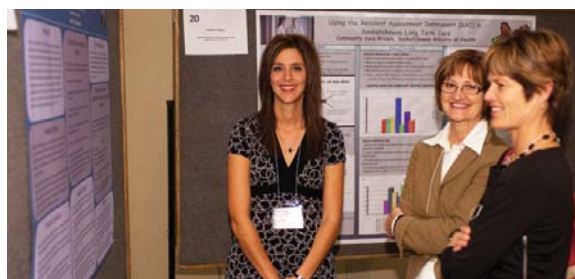
Thursday, October 28th Poster Session Evening



Thursday evening's program included Summit registration and an informal scientific poster session featuring 20 submitted posters and one additional interactive poster which was used to collect feedback from attendees (more information about this poster is highlighted on page 22).

Poster presenters included:

John Keady
Leslie Holfeld
Duane Minish
Lesley McBain
Xiangfei Meng
Julie Kosteniuk
Debra Morgan
Joanne Bracken
Norma Stewart
Catherine Lacny
Nicole Haugrud
Charlene Chipeur
Megan O'Connell
Margaret Crossley
Sheena Walls-Ingram
Chandima Karunanayake
Tracy Danylyshen-Laycock



A separate booklet with all of the posters displayed at the Summit is available by contacting Debra Morgan at debra.morgan@usask.ca. Additionally, poster presenter contact information is available in the contact information section of this report on pages 20 & 21.



The posters remained on display throughout the day on Friday.

CIHR-SHRF Applied Chair in Health Services & Policy Research Program (2009-2014)

- Aim is an integrated program of:
 - Research
 - Mentoring and education
 - Knowledge translation and exchange (KTE)
- Review Criteria
 - Scientific Merit
 - Potential Impact
 - Plans to involve intended users early and often in the research process



Applied Chair in Health Services & Policy Research

- "Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia"
- Funding partners:



Decision Maker Advisory Council Terms of Reference

- To provide input into all phases of the research-to-action cycle
- Activities include:
 - identifying priorities
 - providing advice on communicating with various sectors and accessing study populations
 - evaluating research findings
 - facilitating dissemination and utilization
 - developing policy implications
 - These activities are aimed at achieving the best possible result for health services in rural and remote dementia care.



"Knowledge Exchange"

Involves interaction between decision makers and researchers and results in *mutual learning* through:

- planning
- producing
- disseminating, and
- applying research in decision-making
- is **integrated** throughout the research process:
 - increased quality and relevance of the research
 - more feasible recommendations
 - better uptake

Reference: Canadian Health Services Research Foundation

Decision Maker Advisory Council + Other stakeholders + Research Team

Knowledge Network in Rural and Remote Dementia Care



Summit 1 (Nov 2008)



Summit 2 (Nov 2009)

Goals of this Summit

- Knowledge exchange between and among decision makers and researchers
 - Poster presentations
 - Keynote by international researcher
 - Panel presentations
 - Discussion of research projects
- Identifying gaps in the continuum of care (to inform research, service, policy)
 - Continuum of Care poster: what would the ideal care continuum look like?
- Planning next steps
 - Priorities for the Knowledge Network



Friday, October 29th Morning Introduction

On Friday morning, Dr. Morgan welcomed the attendees, and spoke about the background of the Knowledge Network in Rural and Remote Dementia Care. Much of the groundwork for the Knowledge Network started with a team at the University of Saskatchewan who from 2003 to 2009 were funded by a Canadian Institutes of Health Research (CIHR) **New Emerging Team** Grant: *Strategies to Improve the Care of Persons with Dementia in Rural and Remote Areas*. This New Emerging Team focused on interdisciplinary research, interprofessional training, and capacity development. The Rural and Remote Memory Clinic (RRMC) at Royal University Hospital operates today because of the Team's work to bring a variety of disciplines and technology together to better serve people living in rural and remote areas of the province.

In 2009 Dr. Morgan was awarded a 5 year jointly-funded Canadian Institutes of Health Research - Saskatchewan Health Research Foundation **Applied Chair in Health Services and Policy Research**. Entitled *Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia*, the aim of the chair is an integrated program of research, mentoring and education, and knowledge translation and exchange. The Knowledge Network in Rural and Remote Dementia care is a key activity of this Applied Chair.

The Network is composed of people who make decisions about, or influence, health policies or practice (Decision Makers), research team members, and other stakeholders from around the province. The Annual Summits are hosted as an opportunity for members of the Network to meet face-to-face, and to share knowledge and learn from one another.

Present this year at the Summit are participants representing: the Ministry of Health, Telehealth Saskatchewan, Alzheimer Society of Saskatchewan, Regional Health Authorities, Long-term Care sector, Home Care sector, Nurse Practitioners, Family members, Students, Researchers, the Rural and Remote Memory Clinic team, and others.



Friday, October 29th Morning Keynote - Dr. John Keady

Dr. John Keady of the University of Manchester travelled to Saskatoon to provide the keynote address to the Summit.

Dr. Keady started working in the area of dementia as a Mental Health Nurse and his interest is primarily in early adjustment and transitions through dementia.

He is a member of the Dementia and Ageing Research Theme (DART) group at the University of Manchester, the core values of which include:

- meaningful user and carer involvement as partners in all aspects of the research process
- respect for, and inclusion of, issues of diversity and culture
- interdisciplinary and team working
- seeking to maximise the accessibility, dissemination and impact of their research

Dr. Keady's keynote included background on the history of the assessment of dementia, and an appreciation that there are different perspectives by which to view dementia: a medical model, a social model, and a lay understanding. He also provided an overview of some of his and his team's research, which addresses the stages of dementia and how people living with dementia experience transitions from stage to stage. With a strong focus on the narrative and lived experience of the individual with dementia, Dr. Keady shared a number of his experiences in working with people living with dementia.



Dr. John Keady is Professor of Older People's Mental Health Nursing, a joint appointment between The University of Manchester and the Greater Manchester West Mental Health NHS Foundation Trust. John is a trained mental health nurse and founding and co-editor of the Sage journal 'Dementia: the international journal of social research and practice'. He has a long standing interest in the dementia care, covering practice, research and educational developments, and his PhD on the subjective experience of living with dementia commenced in the early 1990s when he was a community mental health nurse in dementia care.

Diagnosing Dementia: Transitions and Tell-Tale Signs

Presentation split into 4 main areas:

- Summary of our Work in Manchester
- Diagnosing Dementia: Research and Practice Examples
- Future Directions
- Questions and Answers

Dementia and Ageing Research Theme

Clusters

1. Biographical and narrative work
2. Psychosocial interventions
3. Lifestyle and creative arts
4. Education

Transcending themes

- Family-centred practice
- Transitions
- Neighbourhoods



The transition from cognitive impairment to dementia

Older people's experiences

Funded by the NHS Service Delivery and Organisation R&D Programme (2008 – 2010)

Dr. Keady's list of Supporting References as presented during his Keynote is reproduced in Appendix C on Page 26 of this report

Friday, October 29th Morning Panel Discussion



Friday morning's panel discussion *Aging and Dementia in Aboriginal Communities* was moderated by Allison Cammer of the University of Saskatchewan and featured three panelists:



Wendy Hulko of Thompson Rivers University presented *Secwepemc Elders speak about 'your dementia'*.

Shawnda Lanting of University of Saskatchewan presented *Addressing the challenges in neuropsychological screening and assessment of ethnically diverse older adults*.



Lesley McBain of First Nations University of Canada presented on her experiences attending the *National Aboriginal Alzheimer's Disease and Related Dementias (ADRD) Research Network Meeting April 15th and 16th, 2010 in Sudbury, ON*.

Friday Morning, October 29th

Joanne Bracken, Executive Director, Alzheimer Society of Saskatchewan
Dr. John Keady, University of Manchester

In Saskatchewan, the number of hours of care that family members and

friends provide to people living with dementia is expected to rise from approximately 9 million hours today to 30.5 millions hours in 2038.

The report makes five recommendations for a comprehensive National Dementia Strategy for Canada:

- 1- Accelerated investment in all areas of dementia research
- 2 - Clear recognition of the role of informal caregivers
- 3 - Increased recognition of the importance of prevention and early intervention
- 4 - Greater integration of care and increased use of chronic disease prevention and management
- 5 - Strengthening Canada's dementia workforce



Joanne Bracken shared information from the *Rising Tide: The Impact of Dementia on Canadian Society Report* commissioned by the Alzheimer Society of Canada, and a subsequent document commissioned by the Alzheimer Society of Saskatchewan which looks specifically at the impact of dementia in Saskatchewan.

Dr. John Keady then took the podium to share his impressions of year one of the implementation of the *National Dementia Strategy* in England. He provided some of the background policy development that led to the National Dementia Strategy, and shared some of the changes and challenges experienced in the first year of the implementation of the strategy. The multiple objectives of the multi-year strategy have been streamlined into an outcomes-focused implementation plan with four identified priorities.



One year in, the National Dementia Strategy for England's outcomes- focused priorities are:

1. Early Diagnosis
2. Improve quality of care in general hospitals
3. Care Homes
4. Reduce anti-psychotic prescriptions

Friday, October 29th Afternoon - Panel Discussion



Frontotemporal Dementia (FTD)

- The development of behavioral or cognitive deficits manifested by either:
 - A) early and progressive change in personality, characterized by difficulty in modulating behavior, often resulting in inappropriate responses or activities, or
 - B) early and progressive change in language characterized by problems with expression of language or severe naming difficulty, or problems with comprehension or word meaning

McMurray et al. (2005)

Diagnostic Challenges

- The onset of symptoms can be very early (in the 40's or 50's) and is easily mistaken for psychiatric illness
- Diagnosis and care are complicated by the lack of insight in frontal variant patients
- Relatively preserved cognitive skills can result in high-risk behaviors (e.g., driving, work-related tasks)
- Antisocial behaviors, reactive aggression, and abnormal fear can result in dangerous situations

"Red Flags" for possible FTD

- Onset of dementia in mid-life (40's or 50's)
- Early onset of disinhibited or inappropriate behavior
- Loss of social awareness and social graces
- Compulsive behavior; change in eating habits
- Distractibility or impulsivity
- Disordered mood (depression or euphoria)
- Stereotyped speech; changes in language
- Environmentally dependent – stimulus bound

The afternoon panel discussion *Frontal Temporal Dementia Caregivers Telehealth Support Group* featured six panelists including Margaret Crossley and Megan O'Connell from the University of Saskatchewan who lead and coordinate a telehealth-delivered support group. Panelists also included Gladys Beisel, Donna Dalziel, Sheri Mitchell, and Ernie Morgan who are members of the support group and travelled to Saskatoon from rural communities in Saskatchewan to participate in the Summit.

Telehealth (TH) Support Group

- Need to develop this intervention:
 - unique intervention for unique group
 - participants in rural SK – need TH
- Group structure
 - 10 spousal caregivers (8 female) - FULL
 - 6 sites connecting via TH
 - Once monthly for 1½ hrs
 - 1st intervention session in March 2009

Drs. Crossley and O'Connell provided information about Frontotemporal Dementia (FTD) and the diagnostic challenges and behaviours associated with it. Often frontotemporal dementia affects people in mid-life, placing a middle-aged spouse or partner in a caregiving role.

Using telehealth technology to deliver a support group for caregivers of people with FTD was seen as a good fit to a unique group of caregivers distributed throughout the province.

The individual members of the support group then shared their personal caregiving stories as well as their insights on ways to support people living with FTD and their caregivers.

With their permission and assistance, the stories the caregivers shared are reproduced on the following pages.

RESULTS ANALYSED THUS FAR

- Questionnaire data
 - Use of telehealth versus in-person group therapy substantially reduced travel burden (i.e., caregivers saved between 262 and 534 km travel per session)
 - reciprocal non-verbal communication, ability to emotionally connect with others, and ability to spontaneously add to group discussions initially rated as 'good' by all respondents
 - more variability in these ratings (from poor to excellent) when measured at 6 and 12 months



Panel Discussion Ernie's Story



On April 21st of this year my 45 year old wife, Karen, was diagnosed with Behavioral Frontal Temporal Dementia. That diagnosis meant a huge change in my life but ironically meant very little to Karen. Karen does not understand nor care about her condition. I don't think she has ever been happier as she seems to not have a care in the world.

Karen and I had a very strong marriage and we shared everything, decision making, chores, friends and dreams. Now everything has changed. It was about a year ago that our lives started to diverge. After over 20 years of working as a special care aid in a nursing home she was put on leave because she was no longer able to carry out her duties. She had enjoyed gardening and baking but she lost all interest in both. She refused to do any of the household chores, putting them off till the next day. Most of her days were spent watching cartoons on TV or playing games on the computer. At first I became very frustrated with her as I thought she was just being lazy. Nothing was getting done around the house unless I did it. I still have not gotten over the resentment that was built up over that time. Eventually however it became apparent that there was something really wrong. In October of last year I took Karen to see our family doctor. It took numerous visits to various doctors, a CT scan and an MRI but at the Memory Clinic in Saskatoon her diagnosis was confirmed as FTD.

I have had to assume all the responsibilities of running our household and caring for Karen while working full time and bearing the burden of knowing that my life partner is slowly being taken from me. At home I have no one to talk to, to share my day with, bounce ideas off of or to help me vent my frustration. Most nights, after Karen has settled, I find myself overwhelmed by sadness, frustration, anger, helplessness and loneliness. For the most part I have had to suck it up and deal with this on my own. FTD is a rare and not well understood disease. There is very little available in the way of support to meet the unique needs of its caregivers. The support I had always counted on from my wife has been cruelly taken from me. The Telehealth program offered by the Memory Clinic is all that I have. The value of being able to speak with and ask questions of fellow caregivers who understand and accept without question is immeasurable. My only wish is that this program was available to more people.

Over the past months there have been 3 reoccurring themes.

1. From the Doctors I have heard that the road ahead will be long and difficult and that I must take care of myself and get all of the help I can. Karen depends completely on me and if I falter she could be in real trouble.
2. Homecare is whom I am to look to for assistance. From them I hear that Karen's case is very unusual and they don't know how to deal with it. Karen does not require physical care and they do not have the resources to provide the kind of supervisory care she requires.
3. Family and friends are always quick to lend a sympathetic, or I sometimes think curious, ear. The conversations always end with something like "if you ever need anything just call". What I really need is someone to call me, to keep tabs on my well being and to step in when it all becomes too much.

Panel Discussion Ernie's Story *Continued*



As the battle intensifies, the harder we fight and the less able we are to call out for help. One of the most difficult things for me to do has been to make a call for help. Sometimes because I felt I should have been able to do things on my own, sometimes because I did not know who to call or what kind of help I needed but more commonly just because I was mentally exhausted

I have lost so much and my world has been turned upside down. Receiving that diagnosis was the biggest psychological shock I have ever experienced and it put me to my knees at a time when I needed to be my strongest for Karen's sake. I had no one to turn to. I wanted someone to step in and work with me. Someone who had the experience, contacts and the resources at hand to do more than just give sympathetic words. So much more can and should be done for the families of people who have just been diagnosed with FTD. Based on my experience here are some suggestions I have.

1. Immediately an assessment should be done to determine the care givers willingness and ability to care for their loved one. .
2. There should be some training given to caregivers. At this point in time we are all winging it. We have little idea of what to expect and should be better prepared to deal with potential life threatening situations as well as those mundane day to day tasks.
3. And what happens on those days when everything goes wrong. Who can we turn to in an emergency or when we just need an understanding voice with practical advice we can actually use? We need to have someone we can turn to in times like those.
4. There are long term care plans that need to be made. I have to work full time and up to now Karen has been at home alone most days. The time is nearing however, that that will no longer be possible and I don't know what I am going to do then. There are day programs at some nursing homes that run from 9:00 am to 3:00 pm which does not work for me. I can't work halftime hours. We need day programs that are flexible enough to meet the needs of working people such as myself.

I have many wishes related to my experience thus far with FTD and I have one suggestion which would address most of these wishes. We need an advocate to work province wide with the caregivers of FTD sufferers. They can meet with new caregivers and assist them in getting through the most difficult early times. They can be a resource for caregivers as they attempt to deal with issues as they arise. They can advise and assist caregivers as they struggle to make arrangements for the long term care of their loved ones. Someone needs to keep track on a province wide basis what works and what does not. FTD is a rare disease yet there have been a number of occurrences throughout the province. Healthcare providers in Prince Albert should not be left struggling to come up with a plan to care for my wife in Shellbrook when it has already been done in Swift Current or Yorkton or North Battleford. Past experiences must be carried forward regardless of where they happened. They must be evaluated and improved upon. The same mistakes do not have to be repeated in different parts of the province. There is no need to write several books on the subject, we need one book with several chapters.

Panel Discussion Sheri's Story



If it could, my poor clock radio would cringe like a whipped dog as I reach out blindly and slap it, hoping to hit the snooze button. Even semi-conscious, my aim is pretty good and blessed silence reins for another nine minutes. But nine minutes isn't enough and when the music blares again, the inevitable debate begins: breakfast vs. more sleep. Sleep wins and I beat the thing into submission one more time. Another nine minutes and I'm out of options, unless, of course, I want to forego getting dressed and give my home care clients a thrill when I show up at their door in flannel p.j.s. ...

From early morning arguments with the alarm clock to the last blessed moment of the day, follow along on a day in the life of one caregiver as she juggles the needs of a husband with FTD, a farm full of goats and over a dozen Home Care clients. She takes you over 100 km and 18 hours of frustration, humor, sadness and joy. Get to know "Jimmy", from the early morning sleepy head with droopy pull-ups to the computer obsessed kid who spends more hours online than most people spend conscious. Except, Jimmy isn't a kid. He is the love of her life, her best friend...her husband.

By 11:00 a.m. I'm pulling back in the driveway and mentally change gears once more. There are about two dozen things I need to get done today and I sort them into some form of priority as I change clothes. Jimmy's breakfast dishes are in the sink and he's upstairs on the computer. No surprise there. In any given day, he spends more time on that machine than most people spend conscious.

I holler upstairs to tell him I'm on my way outside and can't help but hold my breath, waiting for his reply.

"Want me to come too?"

I sigh and start rearranging the priority list. If Jimmy wants to help, I know things aren't going to go the way I planned. I know I'll spend half the day explaining what needs to be done, then the other half going back to re-do what Jimmy has attempted to "help" with. But I can't tell him no. He needs to feel useful, especially at his age.

The irony is impossible to ignore, for she is a childless woman who now has to deal with a man whose mind and behavior are becoming younger every day. At first, she told people caring for him was like having a ten-year-old, then she started saying seven-year-old. Now, it's a three-year-old.

These days, it seems to take hours for me to unwind and it's after midnight before I finally pack it in for the day. The moment my head hits the pillow, my prayers begin to flow. I always start the same way: "Heavenly Father, thank you for this day and its many blessings..." The truly remarkable thing is, no matter what the day has brought, I really mean it.

And when the day is over, if you are asking yourself why and how she does it, her answer is in one very poignant experience that will forever remind her of why it's all worthwhile.

Panel Discussion Sheri's Story *Continued*



White light gives way to red as I step into the shed and into the blush of the heat lamp hanging in the corner. A white cloud surges up from beneath the light and becomes a dog, the newest mother in our little corner of the world. Her movement disturbs her puppies, who squirm and cry. Their limited perceptions know only that the warmth and security of that big furry body is suddenly gone.

The sound of their desperate cries pierces my heart. I cannot tell them that their mother will return soon, her own belly full, ready to resume her new role as their custodian.

I am a custodian too. God has chosen me for the bittersweet role of steward, to a man whose mind is slowly betraying him, to virtual strangers who live alone and lonely in their declining years, stubbornly clinging to the last shreds of dignity and independence, and to all of the animals who share this small piece of land God led me to.

Yes, God led me here, to this place, in this time, because this is where I need to be. He created me to care for others, for it is by giving, that I receive, by feeding others that I am nourished, by relinquishing parts of myself that I become whole. Pain is an inevitable by-product of the role I have been given, every time I watch the man I love try and fail at something that was simple for him only months ago, every time I go to work and discover yet another client has been removed from our Home Care roster,

their battle to remain independent over for good, and every single time I venture into the farmyard and discover that a brand new or elderly animal has slipped from this world in my absence. I grieve each of these losses, but from the loss, there is gain as well. Every time my heart aches, my soul grows.

And then, as the mother dog settles again around her pups, they burrow deep and urgent cries fade to contented grunts. Stillness descends once again and peace wells up to surround me. There will be more losses, more souls young and old who will leave this little corner of the world, will leave me, but as each of those souls brushes mine, however briefly, I will come away changed. I stand as witness to the rhythm that is life and death, granted by God the rare and beautiful chance to experience both sides to the very fullest a human being ever can.

Because I care.

Panel Discussion Donna's Story



My husband was diagnosed with FTD 2 years ago however I'd been living with a non caring, very different person for 2 years prior to this. As you've heard from Ernie, a diagnosis of FTD is shocking, as it's a non treatable death sentence. We as family members go through all the various phases of mourning and these phases continue and shift through days, weeks and months because just when you feel "okay I think I can handle this newest slide backwards"- this hideous disease moves your loved one to a new low level. This disease takes away your sole mate, your job, your lover, your independence, your friends, your sociability, your humor, your retirement, your meaningful life style and your decision making abilities and leaves in it's place a shell of a person who your spouse once was. This is now my husband, Don who is socially and behaviorally inept.

We, as care givers live with this 24/7 for who knows how many years and we get really tired and frustrated.

So what can the Saskatchewan Government do to make sure everyone wins including the government's bottom line. If supports are put in place to allow us to keep our loved ones at home longer because, let's face it, the newest pandemic of the 21st century is dementia and this disease will bankrupt our health care system if supports are not put in place now, that will allow care givers to keep their loved ones out of long term care facilities and in their own homes.

What does the health care system need to do to facilitate this?

- 1. Increase the availability and hours of adult day care**, as well as hire individuals who could sleep over at the dementia patients home. Flexible hours are a must for young parents which allow these parents to be gainfully employed. Well the same needs to happen for the dementia families, as FTD and many other rare dementias are striking younger adults and these people need full time care, but so often, the healthy care giver needs to quit work to look after their loved one. In my case, I'm costing the government a bundle as I'm on income continuance so I can stay at home with Don; I see both a psychiatrist and psychologist monthly just to keep my head on straight to deal with the sleeplessness and stress in this new hideous life of mine and my medical bills have tripled as my coping strategies need a regular boost as I'm in a constant phase of exhaustion. If there was a system in place that allowed for an individual to sleep at my home, who in turn would get up the 5-10 times a night with my husband, and if there were flexible day care hours for him I might be able to actually work.
- 2. Have emergency respite beds in place** – since doing my research for this report I've talked with wives who've spent the night in a bathtub because they were afraid of their spouse - I've talked to a husband who's spent the night in his car because he couldn't reason with his spouse – there was no place for these people to turn to in such an emergency, except, the psych ward and that's simply not where they should be. So you need to set up an emergency respite for all of us.
- 3. Additional respite beds are needed for all of us** so we can get some sleep, so we can regroup and so we finally get some desperately needed down time. We don't fall into the 75% of care givers who get sick while caring for our spouse

Panel Discussion Donna's Story *Continued*



4. Finally, when our spouse enters long term care, we need to know that effective sensory training happens and that the staff buys into the stunning fact that sensory enhancement and allowing for obsessive behaviors be **treated equally as important** as physical care. This will give staff the **tools to feel safe when dealing with our spouse**. And so importantly, that our spouse does not fall into the 87% reduction of stimuli that most dementia residents suffer from which speeds up their aggressive and/or apathetic behavior. The in-services required can be facilitated by care givers who have a doctorate in "winging it" as we have to do these enhancements daily just to survive the humdrum of the new life we've been dealt. I've started volunteering in the locked ward, "Memory Lane" at the Berb Basset Home in Prince Albert. My hope was to enhance the lives of 2-3 residents daily through sensory stimuli and to my surprise after just our 1st visit we touched and improved the lives of 9 residents. They became more responsive, and less agitated and actually were having fun doing the little activities that are hands on. They became engaged and joyful. They had hope in their eyes. Doesn't everyone deserve this.

You are the people who can champion this cause, you have the means and ways to say this is truly important. Many of these people have given to their communities all of their lives and in our case for half of their lives – don't they deserve to be as respected and important as the neonatal unit or many other departments of a hospital

While you can't reverse FTD and many other forms of dementia you, and only you in the health field, can and must enhance the quality of their lives!

Please champion this cause!

Donna Dalziel – care giver



Panel Discussion Gladys' Story



My husband, Barry was diagnosed with Primary Progressive Aphasia in the fall of 2004 at the age of 49 and passed away in December of 2009.

Our journey between 2004 and 2009 was one full of denial, heartache, frustration and sadness. I would never have believed what this dreadful disease could do to a mind and a body if I had not seen it with my own eyes.

I could discuss all the denial and uncertainties that takes place when your husband is diagnosed or what affairs you need to have in order or about all the hard decisions of taking your spouses drivers license away and preparing for long term care. How family and friends don't know what to do or say and some just disappear from your life. I could discuss how heartbreaking it is when you don't understand what your husband is saying anymore and he does not understand you. I could discuss the fear that exists among the staff in long term care facilities when our loved ones become more difficult to handle or how hospitals are definitely not the place for dementia patients. I could discuss how dementia patients need to be allowed to be independent as long as possible and need to be allowed to pace miles a day, layer clothing, fidget, move things a hundred times. Or on a happier note I could talk about the Rural Remote and Memory Clinic Support group which is fabulous and amazing and how we will need more of these groups. If I could have had this support group at the beginning of Barry's disease, I often wonder how much of a difference that could have played in my coping as a caregiver and my decision making.

There are so many areas of discussion with this disease and how hindsight is 20/20.

Our journey never had a lot of guidance from our health system. I was on my own and didn't know what was behind the next corner and I sure was not prepared for how rapidly the disease progressed. If I could have heard others experiences, maybe I would have been better prepared to know what to expect or had a little bit of forewarning.

I would like to address living wills or health directives and when does one use them. Subjects like wills, Power of Attorneys, health directives and funerals are not what people like to talk about, however, there is great importance in talking about all four so that the ones that are responsible for carrying out these duties understand what you truly want.

Barry and I both had a living will and when we signed these documents it was understood by each of us that we did not want to live in a state in which we could not function independently. But I was to quickly learn how difficult it can be to honor what you know without a doubt are the wishes of your husband.

Barry was placed in permanent long term care in April 2009. In mid July 2009 I received a call from the long term care facility that Barry was being aggressive and endangering the other residents and if the situation escalated they would phone the police. I had no idea what the police were going to do since they did not want anything to do with myself or Barry in April when I called them Barry had become aggressive and left our house about 1:00 in the morning.

To this point the long term care facility had called me regularly when Barry would not take his medication and then I would go over and give them to him.

Panel Discussion Gladys' Story *Continued*



On this particular evening in July my brother and sister came with me and while I attended to Barry they questioned the staff as to why they continually called me at home or work to come to give my husband his medications. This was a Sunday and a week later on the Monday I received a call that Barry had been taken to the psychiatric ward. Barry had a seizure shortly after he arrived and I was told by the psychologist that the long term care facility had been e-mailing him all week to take Barry at the psychiatric ward and he finally agreed. I believe that after that Sunday evening they could not manage Barry because of their fears and they could not get Barry to take his medication and they choose to no longer ask me to assist with Barry's medications even though I was there most evenings.

Barry had 2 more seizures that same morning and went from the psychiatric ward to intensive care as pneumonia had set in.

Barry was restrained (arms and legs) in intensive care which in itself was horrific. This was the time that I should have stepped in with the health directive and asked that they only do what was necessary to keep my husband comfortable.

They began to treat the pneumonia very aggressively, but he was so sick I was sure he would not survive the pneumonia. A few days passed and I knew Barry would not be in agreement with any of what was going on and I finally talked to the Dr and told her to cease the medications and let my husband be. She kept saying "we'll see, we'll see" and I should have been more demanding that she stop and I should have went to whoever I needed to in order for that to happen.

Barry remained in the hospital 3 more weeks restrained 24/7. The Dr's comment to me when Barry came out of the pneumonia was "See doesn't he look great, everything is just great" and my response to her was "no it's not". Barry was then sent to the psychiatric ward for another week.

The events that followed Barry's release back to the long term care facility from the end of Aug to Barry's passing were inhumane. I could not have ever imagined what followed. This was what the Doctor had saved Barry for. If she could have seen what I seen, she may have thought twice about saving a dementia patient with pneumonia again. I had made a terrible mistake not fighting harder for Barry and demanding no treatment.

Barry's last 3 months on this earth were pure hell and knowing I could have possibly prevented that still haunts me. I have not been able to talk to anyone about my husband's last 2 months but I can tell you that I would not allow anyone to visit my husband. No one would ever want to be seen that way. Barry would never have wanted anyone to see him at the beginning stages of the disease, let alone those last months. Knowing your loved ones wishes need to be respected and Doctors need to respect the health directives and stop and consider what they are saving a patient for. If I could not have my healthy Barry back then I needed to let my sick Barry go, as I did not wish for him one more moment the way he was.

Friday, October 29th Afternoon Project Small Group

Project Lead: Vanina Dal Bello Haas - presented by Megan O'Connell
Development and Evaluation of a Telehealth Delivered Exercise Intervention
for Rural-Dwelling Individuals with Memory Problems and Their Caregivers



Summary

Exercise is considered to be an important non-pharmacologic intervention for people diagnosed with cognitive impairment. We are developing and evaluating a Telehealth-delivered exercise intervention for rural, community-dwelling individuals with cognitive impairment and their caregivers. We interviewed 18 consecutive families regarding their current exercise levels and perceptions toward exercise of all forms. Based on these interviews, we created a survey that was mailed to all active Rural and Remote Memory Clinic families. This survey asked about current exercise habits, attitudes toward exercise in general and toward telehealth-based exercise group, community resources for exercise and use of these resources, and preference for exercise based activities. From this survey with a 50% response rate, we found that 51% were interested in a telehealth-based exercise intervention. Willingness to participate in group-based exercise predicted interest in the telehealth based exercise, but attitudes toward physical activity and exercise did not predict interest in a telehealth based exercise intervention. Based on these survey results, we are in the planning stages for a pilot of a small group telehealth exercise intervention. We are currently awaiting ethics approval for this phase and will then begin to contact families and Telehealth Saskatchewan to coordinate the small scale pilot.

Summit Feedback:

- We received a lot of encouragement regarding the importance of this intervention for cognitive abilities and for mood.
- We received some excellent suggestions for how to engage participants who are not interested in the social or group aspects of this form of intervention.
- We also received many excellent suggestions for specific activities to engage in during the pilot exercise intervention, with a focus on making the intervention as engaging and enjoyable as possible. Some suggestions included:
 - Chair/dancing exercises ('sittercise')
 - Multiple suggestions to incorporate a musical component for engagement
 - Group-based competitions that could be fun and encourage the social component of the group exercise intervention.
- We discussed the need to tailor the exercise intervention to participants based on age, activity level, and cognitive abilities.
- We discussed the potential for incorporating a falls prevention education component to the exercise intervention.
- We discussed the need to try to incorporate physical activity and exercise in families' daily lives for maximal benefit and discussed possible methods for tracking day-to-day activity.
- We discussed some potential barriers to participation in the telehealth exercise intervention, which included travel to Telehealth suites and family caregiver availability.

What happens next?

For the pilot project, 3 patients and caregivers will be recruited from 2 sites (yet to be determined) for six bi-weekly exercise sessions. Engagement and acceptability will be assessed with audiotaped telehealth interviews post-intervention, which will be analyzed for themes. In addition, each participant will be asked to complete the SF-12, a physical activity scale and the Seniors Fitness Test pre- and post-intervention. Overall, we received a great deal of positive and extremely useful feedback that we will continue to implement in the next phase of our study.

Friday, October 29th Afternoon Project Small Group

Julie Kosteniuk

Dementia Diagnosis and Management: Advancing Strategies to Support Rural and Remote Primary Care Providers (Primary Healthcare Professionals)



Summary

This project has two parts. The first part consists of a pilot study to identify the support needs of Saskatchewan primary healthcare (PHC) professionals in the assessment and management of people with dementia, with a particular focus on rural and remote practice settings. Data for the pilot study were collected in early 2010 by telephone interview with nine family physicians and five nurse practitioners. Of the 14 PHC professionals, eight practiced in rural settings and six practiced in urban settings. Participants diagnosed dementia in 2 to 15 patients per year, referred 0 to 10 per year, and managed between 2 and 80 patients on a monthly basis. Support needs were practice-related (time and staff), as well as information resources, better referral processes, and educational resources. Barriers to improving dementia care knowledge included distance to travel for continuing education courses, and taking time from patient care. Participants wanted education resources delivered in both the traditional way by conference or weekend seminar with other physicians all together, as well as more self-directed or local, with toolkits and books, by telehealth, Internet or podcast. The most frequently requested topics of education were behavioral management, pharmacology in terms of new drug therapies and the roles of different drugs, and tools to help with differentiating types of dementia. The second part of this project involves a study of family physicians that have referred to the Rural and Remote Memory Clinic. The objectives of this study are to investigate referrals of persons with suspected dementia to specialists, confidence levels in recognizing, diagnosing, and managing patients with dementia, the multiple roles played by family physicians in providing dementia care, and preferences for collaborative care and continuing education. Data collection began in November and will end in January of the next year.

Summit Feedback

- There is a perception that family physicians will refer to the Alzheimer Society if asked by the patient or family.
- Perhaps family physicians refer patients with suspected dementia to specialists because they believe the patient/family want to hear the diagnosis from a specialist.
- International medical graduates must receive education to support persons with dementia.
- Family physicians in rural areas are overworked, and must receive help from nurse practitioners.
- Health regions should have dementia care coordinators, similar to palliative care coordinators.

Summit participants recognized that family physicians need a great deal of support to provide care to persons with dementia and their caregivers. This Summit discussion group underscored the need for research that identifies feasible models of collaborative care that will incorporate the skills and services of additional healthcare professionals.

Friday, October 29th Afternoon Project Small Group

Sheena Walls-Ingram
Caregiver Needs Assessment



Summary

The Caregiver Needs Assessment Study has been launched to help us understand the needs and experiences of informal caregivers of Rural and Remote Memory Clinic (RRMC) patients at three points across the year, following their accompaniment of the patient to their first diagnostic clinic visit. Interested caregivers are interviewed first in-person at the Clinic on the day of the diagnostic assessment, by phone six months later, and again in-person at the Clinic during the patient's one-year follow-up appointment. The study seeks to learn more about the experiences of informal caregivers in a rural setting, beginning at the very early stages of first noticing symptoms, and following these individuals in their caregiving journey during the first year after the patient's diagnosis.

Fifteen initial interviews have been conducted so far. We have learned much about how informal caregivers navigate the health care system while trying to find help and answers for their loved ones.

Summit Feedback

One of the purposes of the study is to better understand how a rural setting impacts the experience of caregiving for someone with dementia. We are discovering that informal caregivers who live in a rural setting often find it difficult to articulate how living "rural" affects their caregiving experience. This may be because they are immersed in it and therefore the situation of the "everyday" doesn't come to mind very often. As one Summit participant put it, "It's like asking a fish to tell us what it's like to live in water...they can't because they don't know anything to compare it to."

We asked Summit participants to offer ideas about how to help caregivers reflect on how their rural setting impacts their caregiving experience. Some participants suggested that we ask more directly about issues identified in other research on the impact of caregiving in a rural setting, such as travel costs and the stigma of dementia. Another participant suggested that we present caregivers with vignettes of a person in a similar situation and ask them to comment on what may be some rural-related issues they face.

Although the caregivers enrolled in our study to date represent a broad spectrum of experience, they represent only a small proportion of the families and friends in Saskatchewan who are caring for loved ones with undiagnosed dementia. While the study includes only RRMC caregivers for now we may consider expanding further to include informal caregivers of people who, for whatever reason, have not received or sought a diagnosis. We asked participants to suggest ways to reach informal caregivers who are not connected with the RRMC. Summit participants mentioned Alzheimer Society support groups as a source, while another offered to be a go-between to invite informal caregivers from her own community.

What happens next?

Analysis of the data is ongoing, and new themes are emerging as we collect more data from the interviews. New caregivers will continue to be enrolled in the study until we feel we have gathered the perspectives of enough people to best understand the rural caregiving experience from diagnosis to one-year follow-up. We will be starting to call back the caregivers who we first interviewed, to see how their experiences and needs have changed over the past six months since a diagnosis was given.

We will use the suggestions made by the Summit participants to include non RRMC caregivers in the study. Our interview guide has been modified in light of the suggestions from Summit participants to better draw out some thoughts from caregivers about what it is like to live in a rural setting under their current circumstances.

2010 Summit Event Evaluation

Over half of the attendees of the summit completed and returned their evaluation forms. Thanks to their comments and feedback we've gained important information about how to improve the next Summit.

Those who attended the poster session felt that it gave them an opportunity to learn more about research, and a chance to meet the research team members. They all felt that the poster session provided good value for their time. We also learned that there is a desire to have the poster presenters more visible to attendees, and more available for discussion. We were pleased to hear that the plan to leave the posters on display for Friday was appreciated.

Most respondents strongly agreed, or agreed that there was a good 'flow' to the day, that the meeting room space was enjoyable, that the day's objectives were met, that they were able to share their opinions and ideas, and finally that it was worth their time to attend the Summit this year. Many of the evaluations contained the observation that the day is rushed and time is short, and that there needs to be more time in the day. This could be achieved by either making the day longer or by having fewer items on the agenda. However, respondents enjoyed the meetings this year,

and really appreciated hearing the presentation from the FTD caregivers group.

Elements of the Summit that people liked best included: The invited keynote speaker, Dr. John Keady; meeting others in the field and sharing information with a group of people all involved in knowledge exchange; the powerful and informative presentations by the FTD Caregiver Support Group representatives.

We heard that for next year's Summit we would do well to make sure that: there is more representation from government and health regions; there is more time for discussion with panelists/presenters, and more time for informal conversations; there continues to be a way to involve families/caregivers and those living with dementia; there is a research methodology/methods discussion at the end of the day; there are more First Nations participants involved; and that more information on treatment and diagnosis is provided.

From the other comments that were shared on the evaluations we learned: the caregiver session was very powerful; perhaps people with dementia could take part next year; the event was well organized and involved participants from a variety of backgrounds which made it so informative.

"Well organized and great content and presenters"

"Great job Dr. Morgan and your team"

"Good opportunity to meet and speak with the different groups"

"It is vitally important we engage family members more and more all the time"

"Best Summit yet"

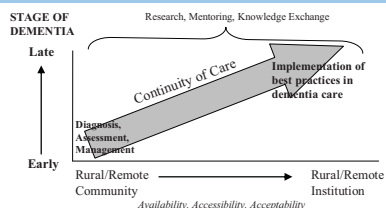
"I learned so much. It was absolutely excellent."

"It was great. A lot of information. Thanks!"

"The representatives from the support group were fantastic and a highlight for the day"

Healthcare Delivery Across the Continuum

Applied Chair in Health Services & Policy Research



Dr. Morgan mentioned in her morning presentation that the title of her **Applied Chair in Health Services and Policy Research** is *Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia*.



One of the aims of this year's Summit was to gather participants' input about what the ideal continuum of care would look like for those with dementia in rural and remote areas. Before the Summit, attendees were asked to provide via e-mail examples of successes or 'areas for improvement' in the delivery of services to people with dementia in their region of the province. Some responses to these questions were sent in and shared during the morning slideshow.

Another tool used was an interactive poster representation of the healthcare continuum from pre-diagnosis/community-based services on one end to long-term care/institution-based services on the other. The poster was printed with notes along the continuum which describe some of the individual research projects undertaken by the research team members. Summit attendees were asked to add to the poster using examples of 'innovations in care' or 'service gaps' in the delivery of services to people with dementia from their community/region. Coloured sticky notes were provided for participants to write their suggestions and add them to the care continuum poster.

An interactive version of this poster will be made available on the Rural Dementia Care website by Spring 2011 at <http://www.cchsa-ccssma.usask.ca/ruraldementiacare>

This year's "assignment": What is new or innovative?



- Tell us about:
 - A *success story* from your workplace, community, or region that led to improved dementia care
 - An *idea* for improving dementia care in your community

■ Issues:

- Activities (e.g., social, exercise groups) and professional services are available to individuals with dementia living in LTC facilities BUT it is difficult for individuals with dementia living at home to get the referrals necessary to access these services
- Recommendations made by specialists (e.g., for physio, exercise, counseling, social interaction) are not always implemented due to workload of rural primary care providers, patient resistance, etc.

■ Strategy:

- Nurse practitioner, nurse, or other local healthcare provider to act as a specific contact person at the local level to coordinate services, track patient progress.
- Would benefit the person with dementia, family caregivers, family physicians

■ Issues:

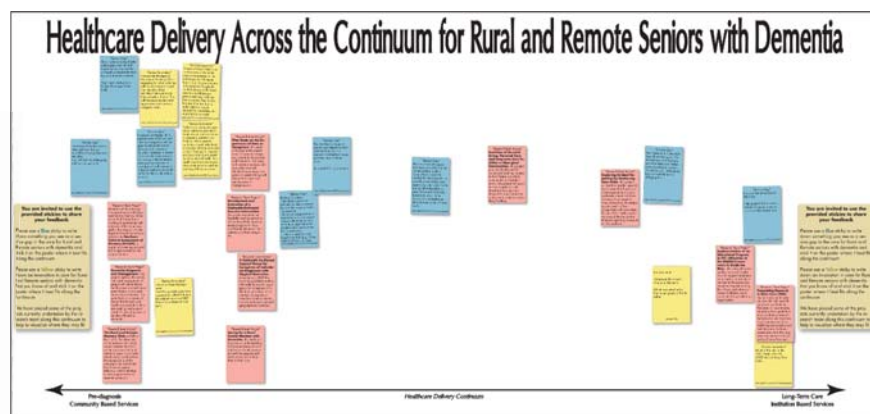
- In rural SK there are few "expert" resources for individuals with dementia and their family caregivers;
- Travel is difficult for older people



■ Strategy:

- Healthcare professionals with expertise in dementia care to provide in-home advice and assistance to family caregivers
 - These experts could train local providers to provide in-home care as needed to provide regular respite for families
- Similar to home care but focused *specifically* on arranging care for those with dementia in rural areas and their caregivers
- Training of professional "experts" and the local healthcare providers could be conducted via Telehealth.
- Telehealth could also be used to debrief, communicate, and collaborate with each other as a means of support for these workers

At the 4th Annual Summit in 2011 this poster will return for attendees to update and make additions





Supplemental Resources

The Summit brought together people from across the province and around the globe who share a common interest in rural and remote dementia care. Pages 20 and 21 of this report include contact information for the Decision Makers Advisory Council and for the Research Team members.

If you are interested in learning more about this year's keynote presenter, Dr. John Keady, you may wish to visit: www.nursing.manchester.ac.uk/staff/JohnKeady

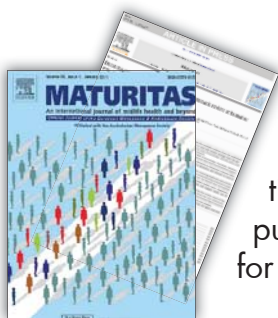
If you did not attend the Summit this year, or if you did and would like more information, we would be happy to provide you with additional resources. You may contact Duane Minish, Research Assistant, at duane.minish@usask.ca or phone: 306-966-4098 to make your request. Available supporting documentation includes:

- Biographies of Decision Makers and Researchers
- Bound copies of all of the posters from Thursday's poster session
- The slide shows presented during the Summit
- The entire binder of information as handed out to attendees is available electronically as a pdf

You are invited to contact Duane as well if you were not able to attend in 2010, but would like to be a part of the 4th annual Summit.

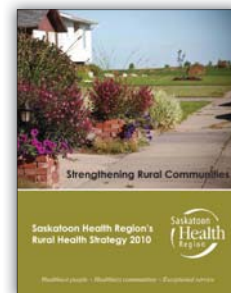
Thanks to Liam Richards for an excellent job photographing the activities of this year's Summit. All of the photos used in this report were taken by Liam.

Update



Researchers Anthea Innes (last year's Summit keynote presenter), Julie Kosteniuk, and Debra Morgan have published two papers which are the result of systematic reviews of rural dementia care literature. Both papers: (a) Dementia care in rural and remote settings: A systematic review of informal/family caregiving; (b) Dementia care in rural and remote settings: A systematic review of formal or paid care are published in the January 2011 edition of the journal *Maturitas*. Full publication details for these articles are available on page 23 of this report.

Since the Summit at the end of October, 2010, the Saskatoon Health Region has released: *Strengthening Rural Communities: Rural Health Strategy 2010*. The Rural Health Strategy has been developed to strengthen Saskatoon Health Region's rural services, and to improve the health and well being of rural residents within the health region. The strategy is available for download from their website at: www.saskatoonhealthregion.ca/about_us/rural_health_strategy.htm



Appendix A:

Decision Maker Advisory Council Contact Information

Contact information has been removed from this version of the report posted on-line.
Please contact Debra Morgan at the University of Saskatchewan
email: debra.morgan@usask.ca or phone 306-966-7905
for assistance contacting any of the decision makers.

Appendix B: Research Team Contact Information

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McBain	Lesley	First Nations University of Canada	306-931-1800 ext 7509	lmc Bain@firstnationsuniversity.ca
Meng	Xiangfei	University of Saskatchewan	306-966-8772	xim443@mail.usask.ca
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Pook	Jocelyn	University of Saskatchewan		jocelyn.pook@usask.ca
Remmen	Moirra	University of Saskatchewan	306-655-2343	moirremmen@hotmail.com
Stewart	Norma	University of Saskatchewan	306-966-6254	norma.stewart@usask.ca
Wagner	Flo	University of Saskatchewan	306-966-2110	flo.wagner@usask.ca
Walls-Ingram	Sheena	University of Saskatchewan	306-966-6154	sheena.walls@usask.ca

Appendix C:

Dr. John Keady's Supporting References

As provided with morning Keynote presentation

- In Press:** Williams, S. and Keady, J. Centre stage storylines: a new method to develop constructivist grounded theory - late-stage Parkinson's disease as a case exemplar *Qualitative Research Journal*
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Appendix D:

Rural and Remote Dementia Care Research Team

Selected Publications

PEER REVIEWED PAPERS

Published/In Press/Accepted:

- Innes, A., Morgan, D., & Kosteniuk, J. (2011). Dementia care in rural and remote settings: A systematic review of informal/family caregiving. *Maturitas*, 68, 17-33.
- Morgan, D., Innes, A., & Kosteniuk, J. (2011). Dementia care in rural and remote settings: A systematic review of formal or paid care. *Maturitas*, 68, 34-46.
- Heggie, M., Morgan, D., Crossley, M., Kirk, A., Wong, P., Karunanayake, C., & Beever, R. Quality of life in early dementia: Comparison of rural patient and caregiver ratings at baseline and one-year follow-up. *Dementia: The International Journal of Social Research and Practice* (accepted May 24, 2010).
- Morgan, D., Crossley, M., Kirk, A., McBain, L., Stewart, N., D'Arcy, C., Forbes, D., Harder, S., Dal Bello-Haas, V., & Basran, J. (in press). Evaluation of telehealth for pre-clinic assessment and follow-up in an interprofessional Rural and Remote Memory Clinic. *Journal of Applied Gerontology*. Available at On-Line First, doi:10.1177/0733464810366564, <http://jag.sagepub.com/>
- Andrews, M.E., Stewart, N., & Morgan, D. (2010). Dementia awareness in northern nursing practice. *Canadian Journal of Nursing Research*, 42(1), 56-73.
- Haugrud, N., Lanting, S., & Crossley, M. (2010). The effects of age, sex, and Alzheimer's Disease on strategy use during verbal fluency tasks. *Aging, Neuropsychology, and Cognition*, 17, 220-239.
- Morgan, D., Crossley, M., Kirk, A., D'Arcy, C., Stewart, N., Biem, J., Forbes, D., Harder, S., Basran, J., Dal Bello-Haas, V., & McBain, L. (2009). Improving Access to Dementia Care: Development and Evaluation of a Rural and Remote Memory Clinic. *Aging & Mental Health*, 13(1), 17-30.
- Lanting, S., Haugrud, N., & Crossley, M. (2009). The effects of age and sex on clustering and switching during speeded verbal fluency tasks. *Journal of the International Neuropsychological Society*, 15 (2), 196-204.
- Jansen, L., Forbes, D., Markle-Reid, M., Hawranik, P., Kingston, D., Peacock, S., Morgan, D., Henderson, S. & Leipert, B. (2009). Formal care providers' perceptions of home and community-based services: Informing dementia care quality. *Home Health Care Services Quarterly*, 28(1), 1-23.
- Forbes, D. & Edge, D. (2009). Canadian home care policy and practice in rural and remote settings: Challenges and solutions. *Journal of Agromedicine: Practice, Policy and Research*, 14(2), 119-124.
- Crossley, M., Morgan, D., Lanting, S., Dal Bello-Haas, V., & Kirk, A. (2008). Interdisciplinary research and interprofessional collaborative care in a memory clinic for rural and northern residents of Western Canada: A unique training ground for clinical psychology graduate students. *Australian Journal of Psychology*, 43(4), 231-238.

Assistance accessing these publications? More information on research conducted by the team?
Please contact Doane Minish, Research Assistant, at:
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Appendix D:

Rural and Remote Dementia Care Research Team

Selected Publications - *continued*

- Steve, T., Kirk, A., Crossley, M., Morgan, D., D'Arcy, C., Biem, J., Forbes, D., & Stewart, N. (2008) Medication use in patients presenting to a rural and remote memory clinic (peer-reviewed letter to the editor). *Canadian Journal of Neurological Sciences*, 35, 669-671.
- McEachern, W., Kirk, A., Morgan, D., Crossley, M., & Henry, C. (2008). Utility of telehealth in following cognition in memory clinic patients from rural and remote areas. *Canadian Journal of Neurological Sciences*, 35, 643-646.
- Forbes, D., Markle-Reid, M., Hawranik, P., Peacock, S., Kingston, D., Morgan, D., Henderson, S., Leipert, B., & Jansen, L. (2008). Availability and acceptability of Canadian home and community-based services: Perspectives of family caregivers of persons with dementia. *Home Health Care Services Quarterly*, 27(2), 75-99.
- Forbes, D., Janzen, L., Markle-Reid, M., Hawranik, P., Morgan, D., Henderson, S., Leipert, B., Peacock, S., & Kingston, D. (2008). Gender differences in use and availability of home and community-based health services for people with dementia. *Canadian Journal of Nursing Research*, 40(1), 38-59.
- Morgan, D., Crossley, M., Stewart, N., D'Arcy, C., Forbes, D., Normand, S., & Cammer, A. (2008). Taking the Hit: Focussing on caregiver "error" masks organizational-level risk factors for nursing aide assault. *Qualitative Health Research*, 18(3), 334-346.
- Kosteniuk, J., Morgan, D., D'Arcy, C. Treatment and follow-up of anxiety and depression in clinical scenario patients: Survey of Saskatchewan family physicians. *Canadian Family Physician*. Accepted for publication.
- Kosteniuk, J., Morgan, D., D'Arcy, C. Diagnosis of anxiety and depression in clinical scenario patients: Survey of Saskatchewan family physicians. *Canadian Family Physician*. Revision in review

TECHNICAL REPORTS

- Lejbak, L., Haugrud, N., and NET Team (2010 revision). *Clinical guidelines and related research for dementia diagnosis*. Report printed at University of Saskatchewan (57 pg).
- Kosteniuk, J., D'Arcy, C., & Morgan, D. (Jan 2010). *Report to physicians on depression and anxiety survey*. Report printed at University of Saskatchewan (10 pages).
- Bergen, A., Morgan, D., & Green, K. (May, 2008). *Dementia care for residents in rural nursing homes: A process evaluation of the Enhancing Care Program*. Report printed at the University of Saskatchewan (42 pg).



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