

Observing and reporting pain: An educational workshop for family members of persons with dementia AKA- Lessons from Kenny Rogers



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Outline

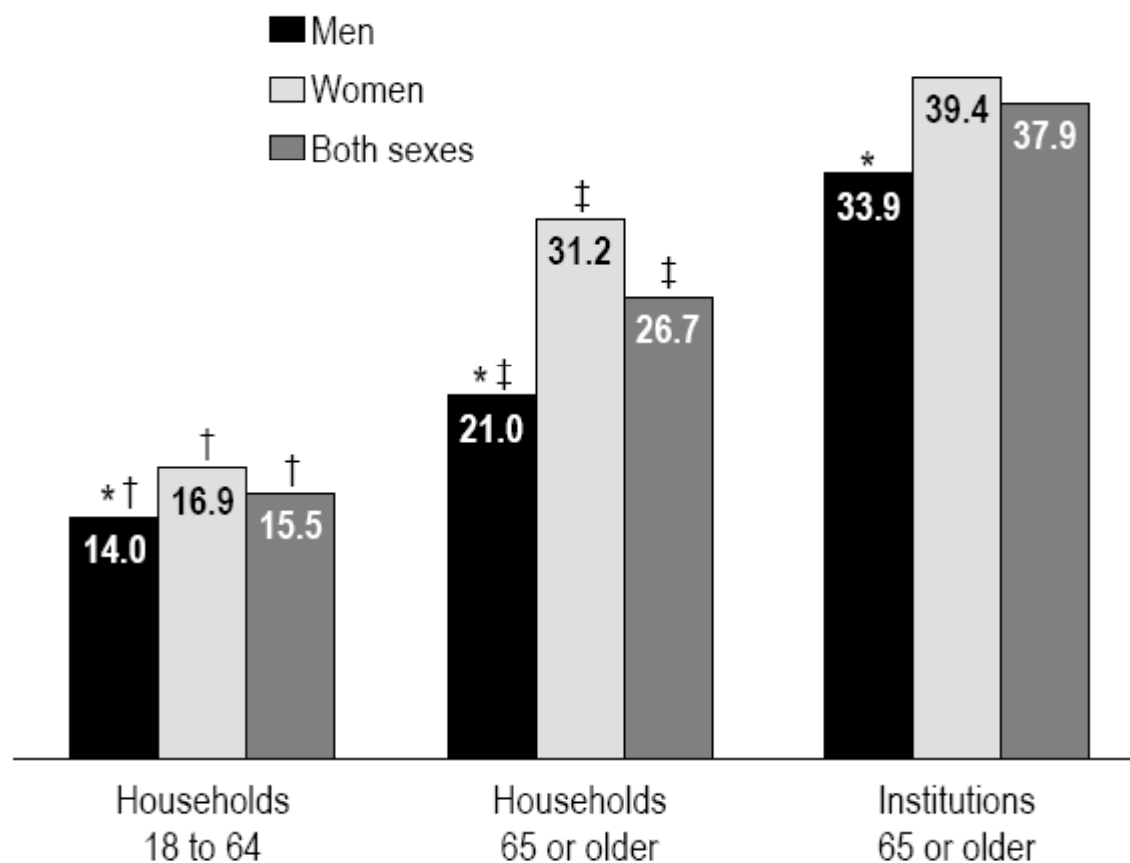
- The team- Agnes Mitchell, Mary-Lou Halabi, Robyn Berry, Joanna Gill
- Background information on pain and dementia
- The Pain & Dementia Knowledge Translation Project
 - Development
 - Field-testing
 - Current activities



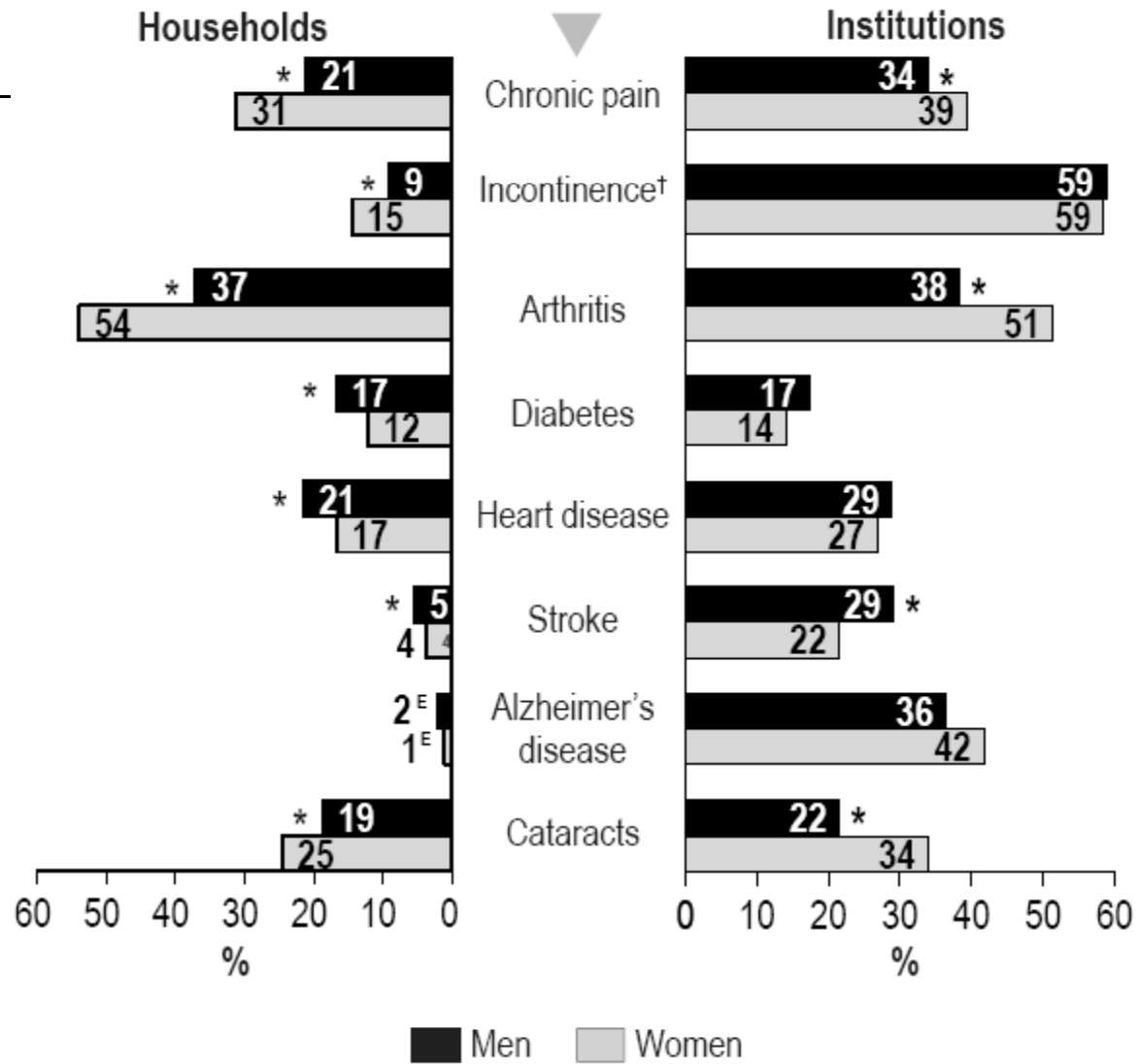
Picture in Canada

- Jones and McFarlane (2005) estimate that **25% of Canadian men** and **28% of women** over the age of 65 experience chronic pain.
- The Health Canada Canadian Study of Health and Aging Report (1998) estimates that **8% of those aged 65 and over** suffered from dementia; **5% of which** have Alzheimer's disease (**28-29,000 AB**).
- concurrently suffer from persistent pain secondary to co-existing chronic illnesses **AND** consequent to symptoms of dementia.

Chronic pain in Canadian seniors (Stats Canada 2008)



Chronic pain and chronic conditions





**ESTABLISHING THE PAIN PROFILE OF
NON-VERBAL LONG-TERM CARE
RESIDENTS WITH DEMENTIA: ANALYSIS
OF ARCHIVED RESIDENT ASSESSMENT
INSTRUMENT (RAI) 2.0 DATA**



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“Just as these leaves obscure what is under the surface, it is difficult to determine the depth of pain experienced by people with dementia”

RAI retrospective analysis – 97 residents in long-term care followed over 12 months

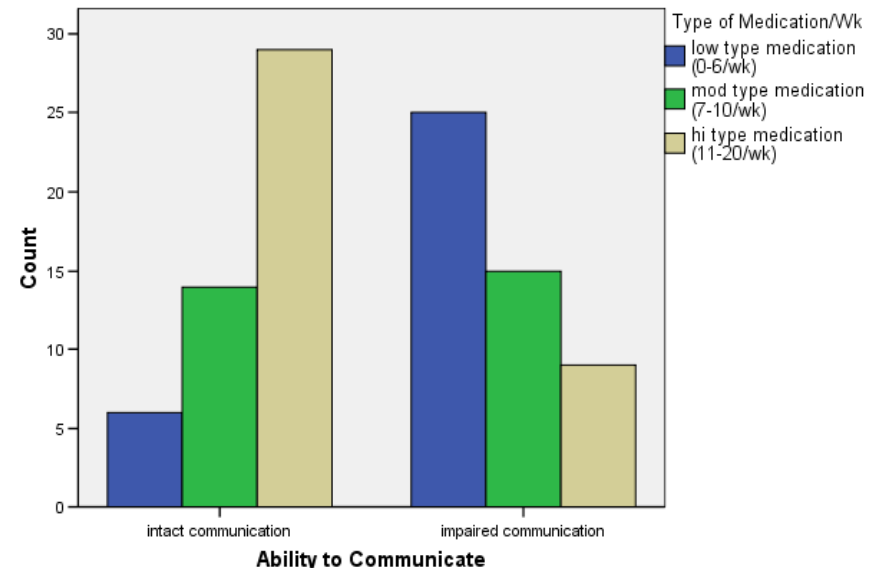
* 49 (50.5%) Communication impaired

* Cognitive Performance Scale scores indicated they had moderate to extensive


cognitive deficit (60% had *extensive impairment*)

- daily pain increased over the 12 month period
- 20.4% were reported as having pain but receiving no analgesic.
- $p < .000$ difference in the average number of any medications (less in C-Impaired)
- $p = .048$ difference in analgesic
- Decreased reports of co-morbidity

Table 1: Range of Medication/Weekly



Brown, CA Pain in communication impaired residents with dementia: Analysis of Resident Assessment Instrument (RAI) data Dementia: The International Journal of Social Research and Practice. 9 (2): _____



The general consensus is that the appropriate use of opiates can lead to significant improvement in the quality of life of elderly persons suffering from chronic pain.

<http://www.clinicalgeriatrics.com/article/1876>

- Opiates, when used within a comprehensive and well-monitored treatment plan, represent an excellent option for the treatment of moderate and severe pain in the elderly. In light of the well-known under-treatment of pain in the geriatric population, it is hoped that the appropriate use of opiates will become standard practice in residential and hospital facilities. As Bernabei aptly states, "Failure to treat pain effectively at virtually all times is no longer acceptable and should be considered a first-line indicator of poor quality medical care."



Incidence of pain flags in communication impaired residents (2006)


8

**Table 2: Daily occurrence of negative 'pain flag' behaviors
(communication impaired residents, n=49)**

Incidence of pain flags in communication impaired residents (2006)			
	%		%
Restlessness	59.2	Wandering	28.6
Reduced interaction	55.1	Insomnia	20.4
Withdrawal	51.0	Repeated verbalization	18.4
Sad affect	51.0	Crying	14.3
Repetitive movement	51.0	Physically abusive	6.1
Resist care	38.8	Verbally abusive	4.1

The RAI's 2 indicators are insufficient-
What about those unable to reliably
verbalize pain?





The challenge- what is pain? What is behaviour? What behaviours indicate pain?

- Australian Pain Society Posters
- <http://www.apsoc.org.au/owner/files/piracf3.pdf>



From the literature we know

○ Body movements

- Immobilization.
- * Purposeless movements.
- * Protective movements and rubbing.
- * Rhythmic movements

○ Facial expressions

- Clenched teeth.
- * Wrinkled forehead.
- * Biting the lower lip.
- * Wide open or tightly shut eyes




Checklist of non-verbal pain indicators (CNPI) Feldt 2000

- Write a 0 if the behaviour was not observed and a 1 if the behaviour occurred, even briefly, during activity or With movement
- 1. **Vocal complaints** (non-verbal): expression of pain not in words--moans, groans, grunts, cries, gasps, sighs -- --
- 2. **Facial grimaces/winces**: furrowed brow, narrowed eyes tightened lips, dropped jaw, clenched teeth, distorted expressions -- --
- 3. **Bracing**: clutching or holding onto side rails, bed, tray table or affected area during movement -- --
- 4. **Restlessness**: constant or intermittent shifting of position, rocking, intermittent or constant hand motions, inability to -- -- keep still
- 5. **Rubbing**: massaging affected area. In addition, record verbal complaints -- --
- 6. **Vocal complaints** (verbal): words expressing discomfort or pain--ouch, that hurts, cursing during movement or exclamations of protest--stop, that's enough -- -- Subtotal score Total score (Feldt 2000b)



Why is this so important?

- Paradoxical effect- increased symptoms of dementia and decreased cognitive functioning with uncontrolled pain
- Because pain =
 - Decreased sleep
 - Homeostasis
 - Respiration
 - Orientation to external environment

- 
-
- Mod/Severe limits to function because of pain = increased chance of falls
 - $P = .0001$ any falls
 - $P = .0156$ multiple falls
- Arinzon et al (2007)



Who better to assess pain than family members?

- Pain observation in non-verbal persons requires time and knowledge
- Families willing/able to assume supported assessment roles (Port 2006)



Barriers to pain management in persons with dementia

[BBC news dementia pain and suffering](#)

The [What about God? - Find Internet TV](#) experience of pain

- Fear
 - Institutionalization
 - Addiction
 - Loss of control
- Stigma
- Caregiver/family communication issues
- Beliefs
 - Stoicism
 - Punishment
 - 'natural'



What did we do?



Stage 1: Canadian Council on Learning Project

- Observing and talking about pain behaviors: A workshop for family members of people with Alzheimer disease and other dementias
 - Toolkit contents:
 - Evidence-based background (educational & Dementia/Pain)
 - CDs of toolkit and Presentations
 - Evaluation forms
 - Posters/planning guides

Observing and Reporting Pain Behaviors:

A workshop for family members of people with Alzheimer disease and other dementias



Who we are

- Sponsored by:
the *Canadian Council on Learning*
- Designed & presented by:
 - Agnes Mitchell, MN, Grant MacEwan College, Faculty of Health & Community Studies, School of Nursing
 - Joanna Gill, MEd & Cary Brown, PhD Department of Occupational Therapy at the University of Alberta, Edmonton Canada



The Myth of Painlessness

Myths are beliefs without facts. It is a myth that people with dementia do not feel pain. We know this is a myth because of the following facts:



- 20% of adults have some form of chronic pain.
- Older people will acquire additional chronic conditions that are often painful (for example diabetes).
- 50% of older people in the community report pain.
- 80% of people living in long-term care have pain.
- Pain is the most frequently reported symptom by older people.
- Most older people have more than one chronic condition so the chances of persistent pain increase as we age.
- Older people tend to under-report their pain.

End of Presentation 1



- Take this opportunity to jot down some notes or questions for the discussion period.

(click the mouse to advance to presentation 2)

Presentation 3: Ways to Recognize Pain



Ask person

Observe for a change in behaviors

Presentation 4: PAINAD Tool



- PAINAD is the name of a tool
- PAINAD stands for Pain Assessment In Advanced Dementia
- PAINAD is used to identify the presence of pain
- PAINAD is used to determine effectiveness of pain strategies
- PAINAD may be used as a communication tool

PAINAD Questionnaire

This form is intended to help you record the pain experienced by your family member. It is important that you put the date and time on log so you can keep track of changes over time and see if patterns appear. It is also important to use the PAINAD both at rest and during activity as pain can change depending on what the person is doing. If you are not sure what some of the terms mean they are defined on the pages after this.

0		1	2	Score
Breathing Independent of vocalization	Normal.	Occasional labored breathing. Short period of Hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None.	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling, or Inexpressive.	Sad. Frightened. Frown.	Facial grimacing.	
Body language	Relaxed.	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console.	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
			TOTAL	



Presentation 5: What to do about pain



- How the PAINAD and the Pain Log can help with:
 - Looking for patterns
 - Finding the right words
 - Sharing pieces of the puzzle
 - Giving feedback

Field-testing

- Sent kits to over 35 community organizations (...*very nice dear...*)
- Set-up our own field-testing workshops (big cost, little return) ...*we are as surprised as you are....*
- Grant submissions (*do you think it is wise to educate families before healthcare providers?*)
- Funded by Alberta Centre on Aging and Canadian Dementia Knowledge Translation Network





What we found-

- emergent contextual barriers when developing innovative programs for caregivers and patients.
 - For example: limited awareness of need, competing priorities for resources, conflicting agendas, healthcare workers beliefs, family members beliefs
- Although they cannot all be anticipated, program designers can learn to engage in an iterative process to allow for creative problem-solving and responsiveness to the local context.



Flawed assumptions

- Legitimacy of message
- Role of seniors' organizations
- Just in time information-



The value of negative knowledge

knowledge formation is not always linear and complex questions can require ~

- *knowing what we do not know,*
 - *knowing what not to do,*
 - *and*
 - *knowing the value of failure.*
- Parviainen & Eriksson, 2006 Int J Management Concepts & Philosophy2(2): 140-153.

Or as Kenny would say....

- "know when to hold 'em, know when to fold 'em".





What we did next-

www.painanddementia.ualberta.ca

- Network/media blitz (professional & media)
- Social Marketing
 - TV
 - Newspaper
 - Paid advertisements
 - Post-cards/magnets/calendars
 - Web news alerts
- Social media marketing
 - Wikipedia

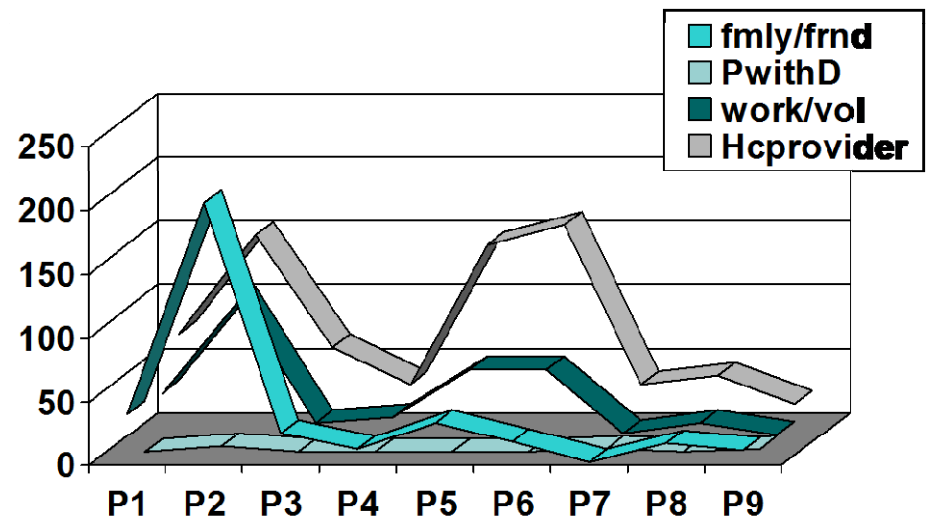


What did we find?

- Between August 24, 2009- December 22, 2009 (4 months) there were **1,251 visits** to the Pain and Dementia website (Jan-April 2010, 500+ visits)
- Moved into the **7th spot on Google** for searches of “pain and dementia”. As people seldom read further than the 1st 10 sites retrieved in a general search of the internet, this position is very positive. Being located within the top 10 ranking makes it more likely that people will continue to access the website.
- Edited externally by **Wikipedia** & embedded in main “Pain” entry instead of cross-referenced.

what is your relationship to someone with dementia?

- healthcare workers (60.8%)
- family/friend of persons with dementia (31.7%),
- workers/volunteers in organizations for persons with dementia (29.3%).
- persons with dementia and healthcare students were infrequent users of the website (<1% and 3.9% respectively).



Where did you hear about the website?

- the internet (28.7)
- from a healthcare worker (27.8%)
- from an agency (19.0%)
- from family/friend (10.8%)
- flyer/postcard (9.2%)
- TV (2.3%)
- 'other' (2%)

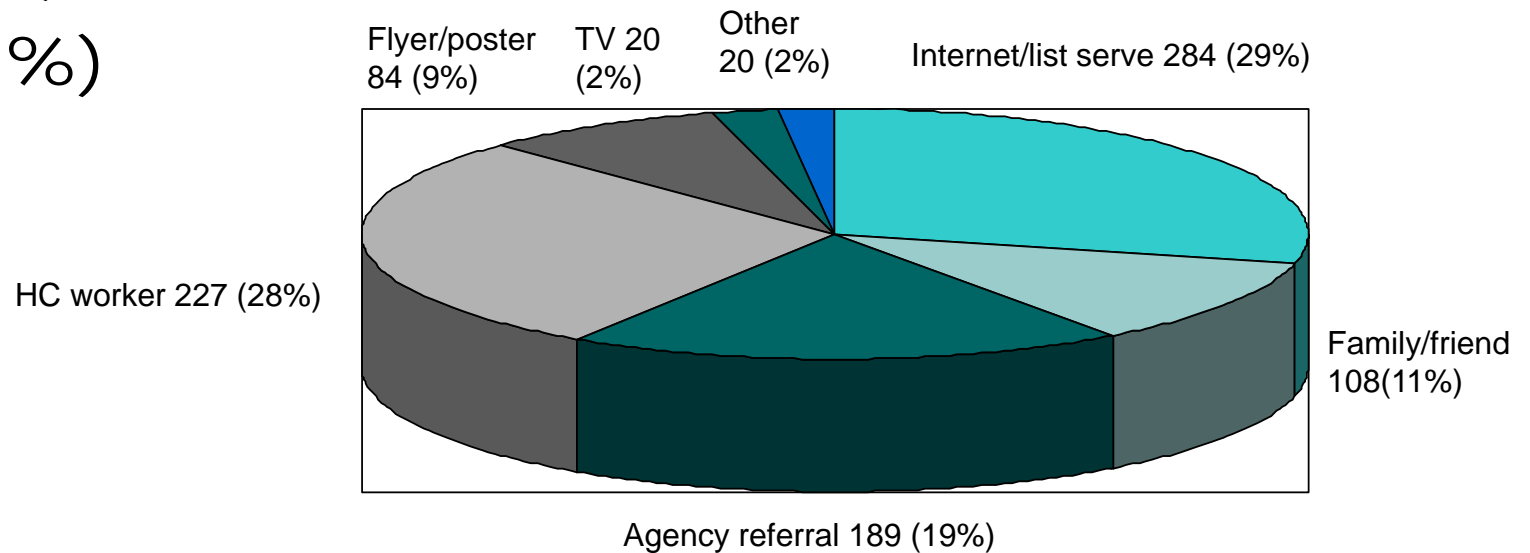


Table 2: Most frequently cited sources of information about Pain & Dementia website

(stated as %, registrants could select more than 1 source)

	Internet	Referral from community or volunteer agency	From a friend/colleague	Referral from healthcare worker	Newspaper	Notes:
Family	41.7	16.9			12.2	*all other sources where the information was available were selected with much less frequency by all registrants- Flyers/posters, TV, online list serves, newsletters, conference. * findings for persons with dementia were not listed because of the low number (n=6)
Friend	32.4		27	18.9		
Worker/volunteer in agency for PwD	27.5	30.2		28.4		
Healthcare provider	20.6	19.3		42.2		
Healthcare student	100	30	40			



Conclusions

- Different methods of letting people know about the website were effective for different groups of registrants
- Overall, web searching seemed the most effective and conference presentations the least.
- Although the majority of registrants were healthcare providers, they seemed primarily to pass the information to other healthcare providers but not to the primary target group- family members of persons with dementia



Next stage

Questionnaire to website registrants-
Use

Sharing patterns & sharing concerns

Advice from the group-

- Questions to ask healthcare providers?
- Questions to ask family members?

Observing and talking about pain behaviors: A workshop for family members of people with Alzheimer disease and other dementias

A Toolkit for providing successful workshops





References

- The PMG Kit for Aged Care
<http://www.apsoc.org.au/owner/files/piracf1.pdf>
- IASP Pain in Older Persons (downloadable resources)
<http://www.iasp-pain.org/AM/Template.cfm?Section=Resources&Template=/CM/HTMLDisplay.cfm&ContentID=2775>
- Australian Pain Association Posters
<http://www.apsoc.org.au/owner/files/piracf3.pdf>
- R.D. Helme and S.J. Gibson. chapter in IASP Press publication: The Epidemiology of Pain ed. I.K. Crombie.
(downloadable chapter) <http://www.iasp-pain.org/AM/Template.cfm?Section=Resources&Template=/CM/ContentDisplay.cfm&ContentID=2955>
- Ramage-Morin (2008) Chronic pain in Canadian seniors- Stats Canada. <http://www.statcan.ca/english/freepub/82-003-XIE/2008001/article/10514-en.htm>
- Family Caregiver Alliance- a personal story.
http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1043



- Kenny and I thank you for your attention and feedback!