

Leading the Way in Continuing Care Conference  
Innovation in Service Delivery  
21<sup>st</sup> November, 2008



# Evaluation of an Outreach Follow-up Service to Clients/Families Receiving a Diagnosis of Dementia

Michele Mew & Carolyn Matthews

Western Health

Cognitive Dementia & Memory Service  
(CDAMS)

# Diagnosis of Dementia



- CDAMS is a specialist diagnostic service.
- Following comprehensive assessment
  - feedback of diagnosis occurs in the clinic
- A range of issues may be discussed:
  - Diagnosis, medications, driving, EPOA, services
- Written summary of feedback
  - posted within 2 weeks

# What is the Problem?



- Clients/families often had difficulty absorbing the information in one session
  - Limited time for emotional responses
- At 4 month clinic reviews
  - apparent that many families often had not grasped the concept of dementia.
  - Had not followed through with recommendations or service referrals.
  - Perceived stigma.

# Desired Outcome



- Provision of a short-term outreach follow-up to clients/families following a diagnosis of dementia
  - Provide better opportunity to understand the concept of dementia, practical implications and emotional responses
  - Reinforce recommendations & coping strategies

# Actions undertaken & Outcomes Achieved



- Literature review
- Focus group with AAV counsellors,
- Liaison with other CDAMS, ACAS's
  
- July 2006 – Dec 2006
  - Approval for additional 0.6 EFT & successful recruitment
  
- Guidelines developed for outreach follow-up
  - All clients diagnosed with dementia
    - Receive follow-up telephone call after written summary
    - Home visit offered

# Literature Review

- Emerging literature on the client/family's experience of receiving the diagnosis
  - For many it is a confirmation of what they expected
  - Provides an explanation for symptoms/changed behaviours
  - Changed outlook for the future
  - Sense of grief and loss, also stigma
  - Adjustment takes time
  - Some studies showed families would have liked more follow-up

## Focus Group with AAV Counsellors

- Communicating a diagnosis of dementia is not a “one-off” event but an ongoing process
- Many clients forget what they have been told in CDAMS Clinic- need time to process
- Families need follow-up support after diagnosis
- There is a need to address emotional reactions and psycho-social issues after diagnosis
- Extra challenges faced by CALD families

# Outcomes Achieved



- Feb 2007-May 2008
  - 107 clients diagnosed with Dementia in clinic
  - All received telephone follow-up
  - 45% clients/families requested and received an outreach follow-up home visit
  - 26 visits jointly conducted with ACAS/AAV
  - Increase in uptake of recommendations & referrals to other agencies

# Evaluation - Survey

- Sept. 2008
  - Survey Questionnaire sent to clients/families who received dementia diagnosis b/w July 2007- June 2008
  - Survey re feedback of diagnosis and outreach f/up
- Good response
  - 41% returned (24 from 58)
  - 46% of these were from CALD (representative of population aged 70+ in service area)
- Respondents were family members not clients
  - All had received a follow-up H/V

# Survey Results

## **Strong Approval for the following procedures:**

- 96% - Clear about why attending clinic
- 96% - Clinic feedback of diagnosis was clear  
(29% would have liked more information)
- 92% - Written summary
- 83% - Post diagnosis f/up telephone call
- 96% - Outreach home visit

## **Additional Services taken up following outreach HV**

- 33%

# Future Directions



- Our evaluation indicates that providing a planned outreach follow-up service to every client diagnosed with dementia is worthwhile
- Provides a foundation for further qualitative research to extend knowledge base in this area.
- Improved practice in assisting clients/families to adjust to a diagnosis of dementia will have wider benefits across the health sector

# Major References



- ◆ Aminzadeh et.al.(2007) 'Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives' *Aging & Mental Health* 11(3),281-290
- ◆ Bamford et.al.(2004) 'Disclosing a diagnosis of dementia: a systematic review' *Int. J. of Geriatric Psychiatry*, 19,151-169
- ◆ Carpenter & Dave (2004) 'Disclosing a dementia diagnosis: a review of opinion and practice and a proposed research agenda' *The Gerontologist*, 44(2) 149-159
- ◆ Derksen, E. et.al.(2006) 'Impact of diagnostic disclosure in dementia on patients and carers: Qualitative case series analysis" *Aging & Mental Health*,10(5), 525-531.