



Alzheimer's
Australia Vic
Living with dementia

Dementia and the World Wide Web

*The Internet is becoming the town square for
the global village of tomorrow ~ Bill Gates*

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Alzheimer's Australia Vic

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Background to the Project

Changing Victorian Demographic:

- The middle-aged children of people with dementia are the key supporters and carers; particularly women
- Consumers are better informed. They come to our organisation with more complex needs and issues, requiring different interventions
- Families and carers are more 'time poor'

Background to the project

Unmet and developing needs:

- There are 'special groups' of consumers who face additional issues such as:
 - People with younger onset dementia (under 65 years)
 - Younger carers
 - Culturally and linguistically diverse communities
 - Aboriginal and Torres Strait Islander communities
- Existing service models are unsustainable in the context of increasing demand and changing consumer needs



“Best Practice Support Services” Project Objectives

- To develop new service models for the provision of responsive, best practice counselling and support for people with all forms of dementia, their families and carers
- To be responsive to emerging consumer needs in Victoria
- To be person and family-centred, with the development of responsive support services to meet the needs of diverse groups
- To be cost-efficient, enhancing sustainability
- To be priority-issue focused
- To be proactive in addressing unmet needs associated with the emerging dementia epidemic
- Success Works commissioned to assist us with this project

Project Approach

- Document current and projected service demand
- Document current service capacity in Alzheimer's Australia Vic and the Cognitive Dementia and Memory Services (CDAMS)
- Document the cost benefits of early diagnosis and intervention
- Document evidence of best-practice service models
- Undertake action research to pilot service innovations, evaluate them and refine the most effective and cost-efficient models
- Analyse the impact of applying new models of service in terms of addressing unmet needs and increasing demand
- Report findings to enable their application with government and with other related services



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Summary of the Literature Review

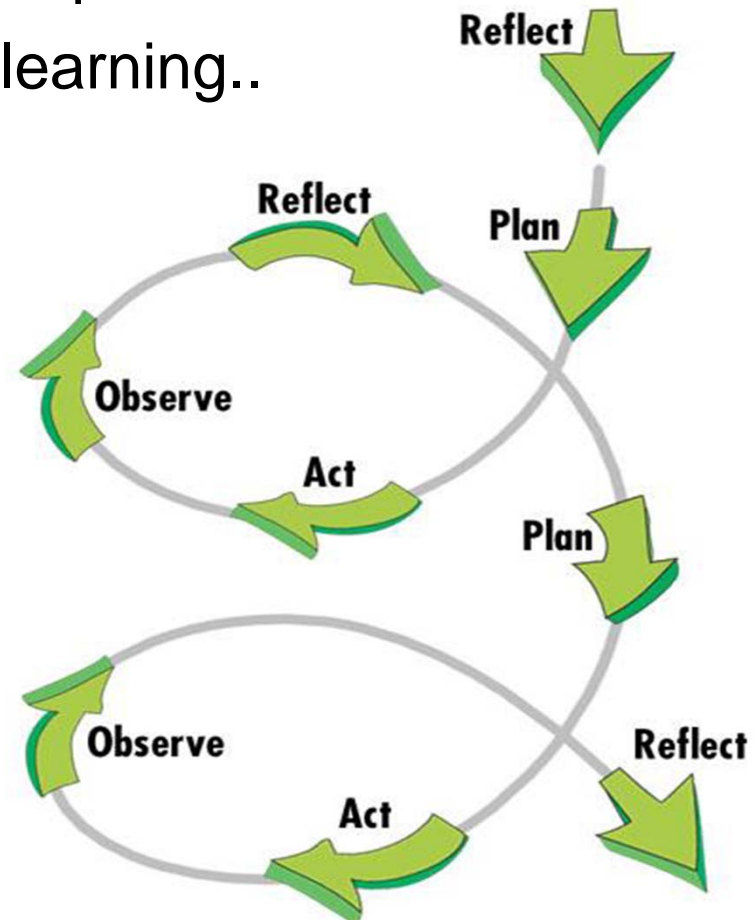
- Overall there is a dearth of research in the support services and counselling for people with dementia
- CBT as a counselling intervention has the greatest demonstrated efficacy
- Telephone and internet interventions are just as efficacious as face to face interventions under certain circumstances
- People with younger onset dementia have specific needs that require a different type of service response
- Dementia affects different population groups differently, and therefore requires a tailored response



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Action Research Framework

- Learning cycle
 - Action research supports participants to take risks
- There are no mistakes – just learning..





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Four pilots selected

- Online counselling
- Online services for people with younger onset dementia
- A comparison of face-to-face vs. telephone-based counselling
- CALD best practice counselling



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Pilot characteristics

- Both utilised the internet to provide support to both carers and people with dementia
- Alternative way in which people could access our services and find support; irrespective of the barriers that many rural and remote people face
- **Online Counselling:** one-to-one text-based counselling, in real time to provide session times when counsellors are available
- **Younger Onset Online Community:**
 - Online forum for people with younger onset dementia and their families and carers
 - Informal 'chat' room



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On-line counselling

- Past decade: marked increase in range of telephone, internet and e-health services in medicine and counselling
- Particularly successful in meeting the needs of younger clients and those proficient with internet-based applications
- Other counselling services locally and international dementia-related peak bodies in the UK and USA have run regular on-line services



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On-line counselling

- Offered via intake and our website
- Opt-in for clients
- Sessions via website link; no additional software required
- Allocated counsellor
- Initial session time established
- Session occurred as real time instant message, not email
- Limited uptake: 7 clients over 3 months



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Learnings

- Screening process missed
- Difficulty assisting clients with technology issues
- Different cues**
- Slower and felt inefficient as a result*
- Need protection from interruptions*
- Great option for some carers who are house-bound or can't otherwise access conventional services*
- Safety in your 'e-personality'*
- Requires intellectual and skill set shift
- Strongly supported by staff, despite low client uptake



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Younger Onset Dementia On-line Community

- three months duration
- over 130 invited participants
- 2 elements:
 - 'real time' discussion (chat) offered twice a week, during the day and at night at scheduled sessions; moderated by a counsellor
 - forum, with facility to post and respond to static discussion threads; moderated via an alert function
- separate website, with a link from our website
- List of FAQs to assist those using the site
- Rules of the room, to guide behaviour
- Opportunity to email the help desk with technical questions



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Younger Onset Dementia (YOD) Online Community Project

Alzheimer's Australia Vic is the peak body representing the interests of people affected by dementia in Victoria

[Home](#)

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Note: You MUST Register to use this website the first you visit here. After that you can LOGIN so we know it's you and you can participate in the conversations herein.

Register: For new users

You need to Register if you don't already have an account

[Register now - click here](#)

Login: For returning users

Username:

Password:

Log me on automatically each visit

This board has no forums.

WHO IS ONLINE

In total there is **1** user online :: 0 registered, 0 hidden and 1 guest (based on users active over the past 5 minutes)
Most users ever online was **4** on Thu May 27, 2010 5:17 pm

Registered users: No registered users

Legend: *Administrators*, *Global moderators*

STATISTICS

Total posts **79** • Total topics **13** • Total members **49** • Our newest member **robertdh**



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Topics for Younger onset chat

[Younger Onset Dementia: types, symptoms, progression and medication](#)

4 Topics

56 Posts

[I have Dementia - What that means for me...](#)

0 Topics

0 Posts

[Everyday life: Coping Mechanisms and Strategies](#)

3 Topics

10 Posts

[Driving](#)

1 Topics

1 Posts

[Employment](#)

0 Topics

0 Posts

[Financial/Legal Issues: Referral, Centrelink, Superannuation, EPoA, Financial counselling, etc.](#)

0 Topics

0 Posts

[Respite and residential care](#)

2 Topics

5 Posts

[Information sharing on services, support groups and activities](#)

3 Topics

7 posts



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Outcomes

Statistics

- Total posts **79**
- Total topics **13**
- Total members **49**
- People with dementia did not take up the invitation to use the forum



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Learnings

- Great enthusiasm and interest generated amongst staff
- Topic headings ignored; people posted anywhere eg “well, here goes..” = 26 posts
- Need to clarify role of moderator in chat – counsellor? silent observer?
- Client feedback:
 - technology user-friendly
 - good for sharing experiences and connecting with others
 - helped with feeling of ‘aloneness’
 - shared wisdom (in the giving and receiving)
 - great for those in rural areas; no need to travel
 - could use forum at any time
 - chat room less convenient
- Lots of future potential!! Nation-wide initiative; ‘talk to the experts’



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Report available

National Dementia Helpline

1800 100 500

An Australian Government Initiative

or

www.alzheimers.org.au

Select Victoria and publications