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Bradford Dementia Group

# Memory services: for what, for whom?

Murna Downs

Trinity College Dublin, May 7 2010

# Why this question?

An illustration

## Overview

- Policy push
- Experience of early dementia
- Experience of memory services
- Implications

# Policy push

# Diagnosis

Significant percentage not diagnosed

A service system in denial

Audit Commission, 2000, 2002; Macdonald and Dening, 2002; National Audit Office, 2008

# A service system that fails:

people with dementia

family carers



House of Commons  
Committee of Public Accounts

## Improving Services and Support for People with Dementia

Sixth Report of Session 2007–08

*Report, together with formal minutes, oral and  
written evidence*

*Ordered by the House of Commons  
to be printed 14 January 2008*

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## Bradford Dementia Group



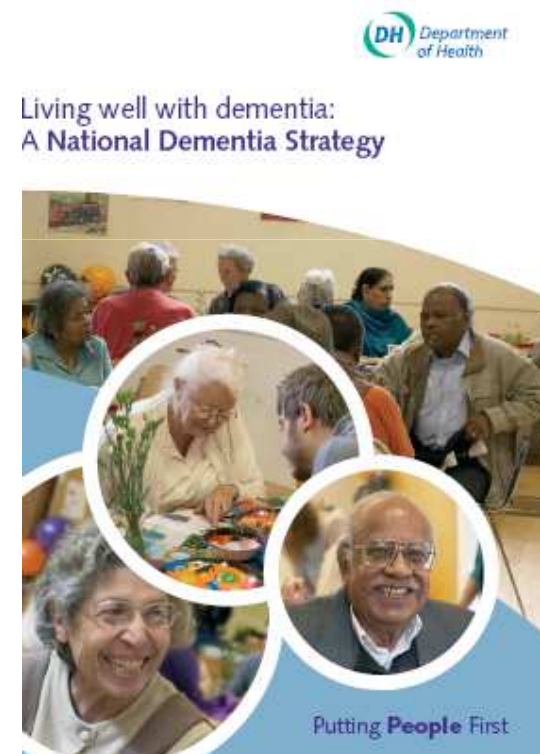
National Audit Office

Improving services and support  
for people with dementia

REPORT BY THE COMPTROLLER AND AUDITOR GENERAL | HC 604 Session 2006-2007 | 4 July 2007

[www.bradford.ac.uk](http://www.bradford.ac.uk)

# Living well with dementia: a national dementia strategy



Department of Health, 2009



# Living well with dementia: a national dementia strategy

Objective 2: Good quality early diagnosis and intervention

Objective 3: Good quality information for those diagnosed

# Memory services

New specialist services for early diagnosis and intervention

Department of Health, 2009

# Experience of early dementia

# Impairments

- Cognitive:      Short term memory  
                         Information processing  
                         Language  
                         Disorientation
- Functional:    Self care

# Living with dementia

Impact of impairments on everyday life (Phinney, 2008)

On what people know, feel, do (Macquarrie, 2005)

# Living with early dementia

Being unsure

Unable to take yourself for granted

Gaps in your day

Can't trust yourself

- Memory problems
- Conversation breakdown
- Disorientation
- Fluctuating awareness

Phinney, 1998

## Feel

Frustrated

Angry

Despondent

Frightened

Sad

Vulnerable

Less sure

Less confident

Macquarrie, 2005; Phinney, 2008

## Do

Withdraw – limit involvement

Practice

Monitor self

Use prompts

Rely on others

Macquarrie, 2005; Phinney, 2008



# Living well with dementia

Trying to be normal and maintain continuity

- Self monitoring
- Keeping an active mind
- Staying engaged
- Downplaying

Phinney, 1998

# Tensions in living with dementia

Self maintaining and self adjusting

Agency and objectification

Clare, 2003; Macquarrie, 2005

# Tension: self maintaining

Keep things normal

- Avoid
- Deny
- Conceal

Cheston, 2005; Clare et al., 2005

## Tension: self adjusting

Integrate into sense of self

Confront

Seek information

Seek solution

Clare, 2003

## Implications for early diagnosis

- Self maintaining – avoid information
- Self adjusting – seek out information

Clare, 2002, 2003

## Tension - agency or object

Autonomous agent

control over one's life

control over defining when have a problem and  
what solution should be

Object – dependent, others decide

Macquarrie, 2005

# Concerns of people with early dementia

n= 48

loss of mind

loss of bodily functions

negative effect on relationships

negative effect on pleasure

Moniz-Cook et al., 2009

## Implications for early diagnosis

- Reluctant to give up control
- Need trust to give up control



# Experience of memory services

## **Expectations and experience of memory services**

n=28

Initially, nervous and apprehensive

Immediately after, satisfied and felt had benefited

Cahill et al., 2009

# Our study of people attending memory services

# Acknowledgements

Jessica Tasker

Clive Baldwin

Michael Jubb

Michelle Place

Elaine Argyle

# People with memory problems

18 participants:

10 men; 8 women

mean age 77

5 live alone; 13 live with spouse

## How information was gathered

Face-face interviews

Immediately before and after first appointment

**They are experiencing changes in their  
memory**

*Somebody can say some'at and half an hour later I haven't a clue what it was.*

*When I wake up first thing in morning I've no idea what day it is. No idea at all.*

*He says: "I have told you this." And my daughter says "I've told you mother," you know. They don't realise it's, it's sort of gone in one ear and out of the other.*



**Over half didn't want help**

## I can live as I want

*My memory is obviously not as it should be but it doesn't seem to affect me, you know what I need to do I feel as though I can do.*

*It's good enough for my everyday run of life.*

*She (wife) does everything for me so I don't really need a memory.*

*I have taught myself to remember. I stop thinking about it, do something else, and lo and behold it comes back.*

*I think most of it's laziness. I don't take much interest when they talk to me you know.*

## Nothing can help

*I think memory's a bit like a, wiping a blackboard;  
it goes and that's it.*

*It's just something you have to face you know  
when you are getting older.*

*I'm 85 now so I don't think they can do much for  
me.*

# I have other more important things to worry about

*I have bother with me legs, I have bother with me feet. And I can't stand up. And I can't walk. So I end up in a wheelchair....[memory] is the least of my worries.*

## Why have they come to memory service?

Their memory changes are a problem for someone else:

Most commonly for family

*This sort of thing [finding out about memory changes] is being forced upon me really because I've got to take note of it. I can't just ignore it.*

# Almost half wanted help



## A better memory...can anything be done

*What I'd like to gain is a better memory to enable me to do more things than I do now, I haven't got a clue how he might be able to do that... I need him to tell me if there's anything that can be done about my current problem...if it can't be done I will just carry on as I am but it would be a bonus if he could make my memory better*

## Get some answers about my memory

*Well I'm feeling alright about it (the appointment). I haven't experienced anything like it before. It's hopeful I may be able to get some answers really you now about my memory. I worry about simple little things that I don't remember. (Tom 65 yr old man)*

## If anyone can do anything about my memory

*I want to know if anyone can do anything about my memory loss, if I can, I don't know if anyone can do anything about it. I'd like to know why I'm forgetting....I do forget and my husband gets ratty when he's told me things more than once and I've forgotten. He's brilliant, he's 80 and he doesn't forget things and he can't understand why I do and I can't understand it either. (Alice 75 yr old woman)*

# Immediately post appointment

**Some found the assessment difficult**

# Shame

*You're only being made aware of defects*

*I don't like making a fool of myself*

# Fear

*I have seen some people with it. And sometimes it's bad for 'em. When owt like that happens to you get a bit worried*

*You'll go in and never come out*

# Stigma

*I thought God, they think I'm going crackers*

*I don't want everybody looking at me when I'm walking in [to the memory service]*



**Most gained in some way**

## Experience contradicts expectation

*I enjoyed it.. From what I were thinking it were going to be like.*

*It was a lot easier than I thought*

*I feel better than I did when she arrived*

## Having the opportunity to talk

*Charming, patient, listened well, spoke very nicely*

*The only thing I have is praise for all*

*It sort of eased my mind about forgetting things*

*Very nice people here I shan't mind coming back.*

## Talk to an expert

*To hear it (about memory) from somebody a bit above, you know that knows something about it*

## Information about memory

*I'm not as daft as what I thought*

*A new outlook. There might be a forgetting that might be able to be done away with.*

*He said it could be one of three things.*

**Some did not**

## No answers

*I can't think the appointment's helped me in any way at all. I've answered a lot of questions but I haven't got any answers. I wasn't able to ask any of my own questions because I spent the whole time answering the assessor's questions.*

## Didn't want anything

*I don't really know what I wanted , I don't think I really wanted anything to be quite honest...I don't feel that I need help really, if I did I've got family around me. I've got 5 girls and a son.*



**Some weren't sure**

# Ambiguous

*It was an interesting interview..reassuring and it helps with your anxiety when you think everything's alright and you seem to cope with it...Well it's made me more aware of them which I don't know if it's a good or bad thing*

## Unsure

*I just hope me brain could be made better or something*

## Benefits

Did not want to be there and did not benefit	7
Did not want to be there and did benefit	4
Wanted to be there and did benefit	3
Wanted to be there and did not benefit	3

## Summary

- Policy push toward early diagnosis
- New services to facilitate this
- Keen-ness of services may not be matched by keen-ness in people
- Those who are keen are seeking solution to memory problems
- Most commonly reported benefit is having the opportunity to talk about their difficulties

# Summary

Looking for:

- Information about what is causing the difficulty
- Someone to talk to about difficulties
- Someone who understands, has expertise, is kind, listens
- Someone who can reassure them it will be ok

## Summary

Helpful to see person's experience of memory service in the context of how the person is coping – resolving tensions between:

- Self maintaining and self adjusting
- Agency and objectification

# Implications

- People do not always see purpose of first appointment at memory service
- See it as something ‘other’ to way of coping
- Those who want something from first appointment at memory service, want information and a cure
- Most report getting an educated and kind ear



# Implications

- People actively cope with living with memory problems
- Need information about role of memory services in helping people live with memory problems
- May need dialogue as much as diagnosis