YOUNGER PEOPLE WITH DEMENTIA
Needs and Barriers

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Birmingham and Solihull Mental Health NHS Foundation Trust
Format

• What do people with early-onset dementia need?
• Local population need: prevalence estimates
• Meeting Needs
• Overcoming barriers
Exercise 1

What do people with early onset dementia say they need from services?
Needs

- Access to timely and accurate diagnosis
- Access to evidence-based treatment (pharmacological and non-pharmacological)
- Access to information and advice to navigate complex systems
- Access to social welfare advice
- Access to Social connectedness
- Access to comprehensive services
How Many People with Early Onset Dementia Live in My District?

- Assume total population of 500,000
- How many dementia cases?
- How many cases of AD?
- How many cases of ‘rare dementia’?
Guestimates

• Total population 500,000 = 150 cases
• Around 2.2% of all dementia is EOD
• Knowledge of local population structure enables a better estimate
• Note studies based on clinical cases underestimate prevalence
Prevalence EOD / 100,000
(Dementia UK 2007)

<table>
<thead>
<tr>
<th>Age</th>
<th>F</th>
<th>M</th>
<th>Tot</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-34</td>
<td>9.5</td>
<td>8.9</td>
<td>9.4</td>
</tr>
<tr>
<td>35-39</td>
<td>9.3</td>
<td>6.3</td>
<td>7.7</td>
</tr>
<tr>
<td>40-44</td>
<td>19.6</td>
<td>8.1</td>
<td>14.0</td>
</tr>
<tr>
<td>45-49</td>
<td>27.3</td>
<td>31.8</td>
<td>30.4</td>
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<tr>
<td>50-54</td>
<td>55.1</td>
<td>62.7</td>
<td>58.3</td>
</tr>
<tr>
<td>55-59</td>
<td>97.1</td>
<td>179.5</td>
<td>136.8</td>
</tr>
<tr>
<td>60-64</td>
<td>118.1</td>
<td>198.9</td>
<td>155.7</td>
</tr>
<tr>
<td>45-64</td>
<td>66.2</td>
<td>99.5</td>
<td>84.7</td>
</tr>
<tr>
<td>65-69</td>
<td>1000</td>
<td>1500</td>
<td>1300</td>
</tr>
</tbody>
</table>
Figure 1. Causes of Dementia In Younger People (Harvey, 1998)

- Alzheimer's Disease: 34%
- Other Causes: 19%
- Vascular Dementia: 18%
- Dementia with Lewy Bodies: 7%
- Alcohol Related: 10%
- Frontotemporal Dementia: 12%
### Numbers for Diagnostic Subtypes

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Percentage</th>
<th>Number / 500,000 pop</th>
</tr>
</thead>
<tbody>
<tr>
<td>AD</td>
<td>34%</td>
<td>51</td>
</tr>
<tr>
<td>VaD</td>
<td>18%</td>
<td>27</td>
</tr>
<tr>
<td>FTD</td>
<td>12%</td>
<td>18</td>
</tr>
<tr>
<td>ARD</td>
<td>10%</td>
<td>15</td>
</tr>
<tr>
<td>DLB</td>
<td>7%</td>
<td>11</td>
</tr>
<tr>
<td>Other</td>
<td>19%</td>
<td>28</td>
</tr>
</tbody>
</table>
Other Dementias (Harvey 1998)

<table>
<thead>
<tr>
<th>Other</th>
<th>Excluded</th>
</tr>
</thead>
<tbody>
<tr>
<td>HD</td>
<td>TBI (625/100,000)</td>
</tr>
<tr>
<td>MS</td>
<td>CVA (235/100,000)</td>
</tr>
<tr>
<td>CBD</td>
<td>HIV?</td>
</tr>
<tr>
<td>CJD</td>
<td></td>
</tr>
<tr>
<td>CO</td>
<td></td>
</tr>
<tr>
<td>DS</td>
<td></td>
</tr>
<tr>
<td>PD</td>
<td></td>
</tr>
<tr>
<td>????</td>
<td></td>
</tr>
</tbody>
</table>
Other Dementias (WADS)

- HD
- MS
- CBD
- ???
- HIV
- HC
- SOL
- CADASIL
- SCA
- PML
- CTE
- Takayasu’s disease!
Diagnostic Needs

- High rate misdiagnosis (30%-50%)
- Potentially reversible causes
- Carers report diagnostic delays
- Psychiatry, Neurology, Radiology, Genetics
- ‘Hi tech’
- Coordinated not ‘pillar to post’
Need to Avoid Misdiagnosis!

- English not first language!!!!!
- Past history of schizophrenia!!!!
- Past history of depression or BD!!!
- Learning disability
- No or unreliable informant
- Substance misuse / prescribed drugs
- Malingering – problems with effort tests
Early Onset AD

- Occupational dysfunction may precede overt memory impairment
- MRI atrophy pattern may differ
- Atrophy of posterior cingulate (Shinno 2008)
- Atrophy of precuneus (Karas 2007)
- Myoclonus more common
- Generalized seizures more common
Treatment Needs

- Treatable / reversible dementia
- Diagnostic heterogeneity
- Higher expectations
- Involvement in research
- Behavioural problems – greater risk
Treatable ‘Dementia’

- HC
- HIV
- PML
- SOL
- ARBD
- VaD
- Takayasu’s

- Valproate
- Other drugs
- Depression
- Hysteria
- Schizophrenia
Medical Interventions

• ACHEIs for dementia in AD
• Memantine for dementia in AD
• ACHEI for dementia in PD
• Risperidone for AD aggression
• Antipsychotics for AD BPSD
• Carbamazepine for AD BPSD
• Trazodone for FTD BPSD
• ACHEIs for AD BPSD
• Antidepressants for AD depression
Research (RCT)

- AD2000 / AD2000 Aspirin
- MRC-CALM-AD
- MRC-DOMINO-AD
- HTA-SADD
- TauRx 007 (P2 bvFTD)
- HTA – ATILLA
- HTA - ATLAS
Promoting Positive Mental Health and Well-being

• Equal access to evidence-based interventions with address specific mental health needs

• Promoting welfare access and social connectedness: access to roles, relationships, resources, purpose

• Encouraging self-advocacy, personal responsibility and self-care: information and advice, education, advanced care planning, successful navigation of complex systems
Strategies for Promoting Independence

- Function in ADLs often deteriorates below what expected by illness
- Little high-quality research from which to draw conclusions
- Longitudinal and individual response as needs change (care planning)
- Combining interventions
- Maximising use of individual strengths and retained skills
- Continual engagement in roles and activities: Social network, voluntary sector, local communities (partnerships)
Strategies for maintaining cognitive function

• Reasonable evidence to support use of Cognitive Stimulation approaches with people with mild to moderate dementia
• Cog Stimulation adds to effects of Donepezil in both mild and moderate AD

“All people with mild-to-moderate dementia of all types should be given opportunity to participate in a structured group cognitive stimulation programme”

Non-cognitive Symptoms and Challenging Behaviour

Behaviour that challenges
• No evidence that standardised approaches (validation, cog stim., reminiscence) have impact
• Aromatherapy - 2 controlled trials
• Music-based approaches, MSS to be evaluated (2006)
• Behaviour management approaches – single case studies

Depression and Anxiety
• CBT, MSS, relaxation training, pet therapy
• CBT with active carer involvement: 1 RCT (Teri et al, 1997) (additional impact on carer depression)
• Qualitative evidence points to value of groups for support (particularly at point of diagnosis) and social activity (PROP Group, 2005)
Kong et al (2010)

- Cochrane review – non-pharmacological interventions for agitation
- Moderate reduction in 3 RCT’s of sensory interventions (aromatherapy, music, hand massage)
- No significant effects for social contact, activity intervention, environmental modification, caregiver training, behaviour therapy
Hulme et al (2010)

- Systematic review of non-pharmacological approaches that informal care-givers might try
- Weak study designs and small sample numbers
- Music, hand massage, physical activity/exercise

- Service providers should explore structured group approach provision, particularly music therapy and physical exercise
Equal Access if not Age Appropriate?
The WADS approach to Cognitive Stimulation

Cognitive stimulation Therapy
• Low acceptability of standardised CST among younger people and professionals
• Increasing acceptability by change in activities
• Pilot planned for June 2011
• Most suitable for people with more moderate difficulties?

Reading for Well-being groups
• Use of poetry / short stories
• Stimulation of discussion about material, seeking opinion, reminiscence
• More everyday?
• Participants stress value of meeting together, and feeling connected
• Most suitable for people with early dementia?
Information Needs
The Person, Dementia, and Complex Systems

• Education about Dementia, specific advice to manage challenging situations
• Education about Systems: health-care, social care, 3rd sector
• The Person as the educator: Life Story work

• At the right time, in the right way, by the right person
• Staff with an “information” mind-set: Belief in the value of education for people
Hierarchy of Needs

Mazlow's Hierarchy of Needs

- **Physiological**: breathing, food, water, sex, sleep, homeostasis, excretion
- **Safety**: security of body, employment, resources, morality, the family, health, property
- **Love/belonging**: friendship, family, sexual intimacy
- **Esteem**: self-esteem, confidence, achievement, respect of others, respect by others
- **Self-actualization**: morality, creativity, spontaneity, problem solving, lack of prejudice, acceptance of facts

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getting better together
Information Needs
Social Welfare

- Maslow’s hierarchy – Level 2 (and 1)
- Health provision alone is not enough

Social welfare needs
- Financial resources and Debt issues
- Housing issues
- Employment: terms and conditions, ending work, working whilst caring, working after caring
- Voluntary work
WADS / CAB partnership project
Expert Social Welfare Advice for People with EOD

• 12 month project funded by Birmingham Council grant
• 2.5 days a week ring-fenced CAB advocate (telephone helpline, bookable one-to-one appointments, information groups, voluntary work resource directory)
• Enables each partner to focus on core-business whilst working together to achieve optimal impact on well-being
• Quantitative Evaluation: impact on resources, impact on health-related quality of life, and care-giver burden
WADS / CAB partnership project
Expert Social Welfare Advice for People with EOD

• “you can never get enough advice, and we had a lot of problems in the first year because the benefits office always treat you like you are trying to get something for nothing. To be honest, we would have been lost without her advice. She was there when you needed to ask her questions. She has helped me to fill out forms over the phone and then she will phone you up to see how you have got on”

• “she has been very helpful with financial things when we were really stuck, and owed people money; she has helped us in reducing the payment and making it more comfortable for us. She advised us on income we are entitled to…all the benefits”

Birmingham SHA Innovation in Dementia Care (2010) award
• What do you consider to be the service priorities?
• You have 3 WTE (or equivalent part time) staff funding
• What staff would you choose for your team?
Barriers!

• GP purchasers want one size fits all dementia care!
• Government want one size fits all dementia care!
• Can’t have service access based on age!
• “Silo mentality” – healthcare provision alone is not enough
• Complexity and cost not reflected in PBR!
• Dementia advisor rules – fragmentation model!
• Signpost but no destination!
Solutions?

• If services cannot be provided on the basis of age how can the needs of younger people with dementia be met?
• Return to one size fits all dementia care?
• Services based on complexity?