The National Dementia Strategy for England

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Background selected highlights

- NSFOP
  - there, but little impact
- Forget me Not, Audit Commission
  - largely forgotten
- Everybody’s Business
  - ...but not a lot to show
- NI CE/ SCI E Guideline
  - very long list of stuff we don’t do
- Dementia UK
- NAO value for money report
- National Dementia Strategy
The impact of dementia in the UK

Dementia UK report
Meeting the challenge of dementia
Consensus estimates of the population prevalence (%) of late onset dementia
683,597 people with dementia in the UK today

“700,000”

In 30 years - doubling of prevalence to 1.4 million

424k in the community (64%)
244k in care homes (36%)
Dementia UK Results

Total cost of dementia in the UK
£17 billion per annum

Projected increase in costs of dementia

Total cost of dementia projected in the UK in 30 years
£51 billion per annum
Dementia UK Results

Variation in services for people with dementia – a case study of prescriptions per year per person with dementia 2005-6

[Map showing variation across different regions]
Proportion of estimated number of people with AD in Europe treated with anti-dementia drugs 2004
NAO Report - Value for money in dementia services - key findings

- Size and nature of challenge
  - Big and growing
  - Doing nothing should not be a strategic option

- Need for early diagnosis and intervention

- Disjointed services in the community

- Opportunities for increased cost effectiveness
  - “spend to save”
PAC report

PAC 8 findings

1. High priority
2. Explicit ownership and leadership
3. Early diagnosis
4. Improving public attitudes and understanding
5. Co-ordinated care
6. All for carers too
7. Improve care in care homes
8. Improve care in general hospitals

- Presented by committee as its most important report of the year
- Review this year
National Dementia Strategy development

- 12 month programme
- Develop
  - National Dementia Strategy
  - Implementation Plan
- First explicit prioritisation
Key themes of draft Strategy

- Improving awareness
- Early and better diagnosis
- Improved quality of care
- Delivering the Strategy
1. Improving awareness and understanding
Barriers to care: public and professional attitudes and understanding

- Stigma of dementia prevents discussion
- Inactivity in seeking and offering help
  - False belief: normal part of ageing
  - False belief: nothing can be done
2. Early diagnosis and intervention

memory services
information
continuity/ constancy
The fundamental problem

- Only a third at most of people with dementia receive any specialist health care assessment or diagnosis.
- When they do, it is:
  - Late in the illness
  - Too late to enable choice
  - At a time of crisis
  - Too late to prevent harm and crises
An example of an early intervention service - the Croydon Memory Service Model

- A new way of doing new things with a new population
  - medium cost
  - good quality
  - high throughput
  - assessment and care service
  - for people with dementia and their carers

- UK DH national dementia pilot
- Designed to be reproducible
The work

- All team members trained in generic assessment
- Referrals from GPs and social services ( الصحيح: open)
- Home assessment in pairs (patient and carer)
- Manualised assessment with standardised tools
- Diagnosis and management plan at team meeting
- Systematic feedback of diagnosis and plan
- Social care package as needed
  - all members can access services directly
- Psychological care
  - carer and patient, group and individual
  - memory retraining, information, support
- Medication
- Continuity of care
- Review
Good quality care

95% acceptance rate

94% appropriate referrals

18% minority ethnic groups

19% under 65 years of age

Outcome: improvement in self-rated quality of life - DEMQOL

- Part of routine assessment
- Preliminary data
- 109 cases
- 6 month follow-up
- $p=0.029$

Outcome: improvement in proxy-rated quality of life – DEMQOL-Proxy

- Part of routine assessment
- Preliminary data
- 141 cases
- 6 month follow-up
- $p=0.041$
Outcome: decrease in behavioural disturbance - NPI

- Preliminary data
- 90 cases
- 6 month follow-up
- $p=0.001$
Providing early intervention services

On balance heavily positive to have the diagnosis if it is done well

- harm prevention
- enabling choice
- better for patients better for carers
- long term savings

- Make diagnosis well
- Break diagnosis well
- Support and care immediately from diagnosis

Carpenter et al (2008), JAGS
Quantity can be quality – penetrance into pool of unmet need

- If there is intrinsic value in assessment
  - the giving of a diagnosis enabling choice
- 300 case target met 2005
- Rising in 2006 to 450 with co-workers from teams
- I.e doubling the number of new cases seen
- Any solution needs to be one that can manage high volume

Penetrance into incident cases of dementia

- 2004: 10%
- 2005: 20%
- 2006: 40%
- 2007: 60%
The power of peer support and learning

- Why do we not use the lived experiences of people with dementia and their carers?
- Why do we only focus on the most severe and complex cases?
- Why not include an imperative for self help and prevention?

EARLY DIAGNOSIS FOR ALL CHANGES THE WHOLE GAME

- Peer support for all
  - Carers
  - People with dementia
- Minimal resource
  - Third sector lead
- Change help seeking
  - Expectations
  - True personalisation
Theme 3 - Improving quality of care

Recommendations

6. general hospitals
7. joint commissioning
8. respite care
9. intermediate care
10. home care
11. care homes
12. registration and inspection
Distribution of DEMQOL scores by CDR score
Distribution of DEMQOL-Proxy scores by CDR score
Change in DEMQOL for those below mean (<90)

- 6 month DEMQOL change 8.3pt, paired t=4.99, p<0.001, Cohen’s $d = 0.79$
- 12 month DEMQOL change 7.8pt, paired t=3.88, p<0.001, Cohen’s $d = 0.60$
Theme 4 - Delivering the strategy

Local implementation, regional support, national co-ordination

13. information
14. research
15. Support for implementation
Clinical/ cost effectiveness
Joint commissioning of services along a defined care pathway to enable people to live well with dementia

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<th>Early diagnosis and support</th>
<th>Living well with dementia</th>
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making the change

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<td>014 joint local commissioning strategy and world class commissioning</td>
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<td>017 effective national and regional support for implementation of the strategy</td>
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Early intervention for dementia is clinically and cost effective – “spend to save”

- 215,000 people with dementia in care homes -- £400 per week
- Spend on dementia in care homes pa
  - £7 billion pa

- 22% decrease in care home use with early community based care
- 28% decrease in care home use with carer support (median 558 days less)

Quality - older people want to stay at home, higher qol at home

- Take an additional 220 million pa
- Delayed benefit by 5-10 years
  - Strategic head needed
- Model published by DH
- 20% releases £250 million pa y6
Cost effectiveness

- The Net Present Value would be positive if benefits (improved quality of life),
  rose linearly from nil in the first year to £250 million in the tenth year.

- This would be a gain of around 6,250 QALYs in the tenth year, where a QALY
  is valued at £40,000, or 12,500 QALYS if a QALY is valued at only £20,000.

- By the tenth year of the service all 600,000 people in England then alive
  with dementia will have had the chance to be seen by the new services

- A gain of 6,250 QALYS around 0.01 QALYs per person year.

- A gain of 12,500 QALYS around 0.02 QALYs per person year.

- Likely to be achievable in view of the rise of 4% reported from CMS.

- Needs only
  - a modest increase in average quality of life of people with dementia,
  - plus a 10% diversion of people with dementia from residential care, to be cost-effective.

- The net increase in public expenditure would then, be justified by the expected benefits.
Final thoughts
Quality improvement in dementia requires:

- vision
- system change
- ambition in scale
- investment
- commitment over time
- leadership
Dementia care pathway

1. Encourage help seeking and referral
2. Locate responsibility for early diagnosis and care
3. Enable good quality care tailored to dementia
Thank you!