Dementia in younger people

Alistair Burns
A 5 year backward glance

- Awareness at an all time high
- Antipsychotics reduced by 50%
- Diagnosis rates up from one third to two thirds
- A hospital dementia CQUIN
- Two primary care enhanced services
- > 600,000 NHS and social care staff had dementia training
- 1.5 m dementia friends
- 150+ Dementia friendly communities
- £60m in dementia research plus £250m for a Dementia Research Institute
- Two PM Challenges
- Record numbers taking part in research
NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

<table>
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<tr>
<th>PREVENTING WELL</th>
<th>DIAGNOSING WELL</th>
<th>SUPPORTING WELL</th>
<th>LIVING WELL</th>
<th>DYING WELL</th>
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<tr>
<td>Risk of people developing dementia is minimised</td>
<td>Timely diagnosis, integrated care plan, and review within first year</td>
<td>Access to safe high quality health &amp; social care for people with dementia and carers</td>
<td>People with dementia can live normally in safe and accepting communities</td>
<td>People living with dementia die with dignity in the place of their choosing</td>
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**“I was given information about reducing my personal risk of getting dementia”**

**“I was diagnosed in a timely way”**

**“I am able to make decisions and know what to do to help myself and who else can help”**

**“I am treated with dignity & respect”**

**“I get treatment and support, which are best for my dementia and my life”**

**“I know that those around me and looking after me are supported”**

**“I feel included as part of society”**

**“I am confident my end of life wishes will be respected”**

**“I can expect a good death”**

**STANDARDS:**

**Prevention(1)**

Risk Reduction(5)

**Diagnosis(1)(5)**

Memory Assessment(1)(2)

Concems Discussed(3)

Investigation

Provide Information(4)

Care Plan(2)

**Choice(2)(3)(4)**

BPSD(5)(2)

Liaison(2)

Advocates(3)

Housing(3)

Hospital Treatments(4)

Technology(5)

Health & Social Services(5)

**Integrated Services(1)(3)(5)**

Supporting Carers(2)(4)(6)

Carers Respite(2)

Co-ordinated Care(1)(5)

Promote independence(1)(4)

Relationships(3)

Leisure(3)

Safe Communities(3)(5)

**Palliative care and pain(1)(2)**

End of Life(4)

Preferred Place of Death(5)

**REFERENCES:**


**COMMISSIONING GUIDANCE:**

- Develop commissioning guidance based on NICE guidelines, standards and evidence-based best-practice.
- Agree minimum standard service specifications, set business plans, mandate and resources.
- Work with ADASS, PHE & other ALBs on co-commissioning strategies to provide an integrated service.

**MEASUREMENT:**

- Develop Quality, Access and Prevention metrics to form the basis of the CCG scorecard.
- Identify data sources and agree with HSCIC, etc on the extraction processes.
- Set ‘profiled’ ambitions for each metric, to form the basis of the transformation plan.

**TRANSFORMATION, RESEARCH, INNOVATION, TECHNOLOGY, PATIENT ENGAGEMENT AND BEST-PRACTICE:**

- Transformation: using CCG scorecard to set & achieve a national standard for Dementia services.
- Intervention: Intensive Support Team to provide ‘deep-dive’ support and assistance for CCGs that fall short.
- Innovation: Intel from Research, Patient involvement, best-practice and technology to influence change.
Count and rate of dementia diagnoses 2010 - 2016

From April 2015, the diagnosis rate indicator includes only patients aged 65 and over and is based on prevalence estimates from CFAS II rather than Alzheimer’s Society method. National ambition is to have two thirds (66.7%) of patients with dementia to have been diagnosed. A dementia diagnosis is counted when there is a record of the diagnosis on a patients’ GP record (QoF Dementia register). Diagnosis rate is the number of actual diagnoses divided by the estimated prevalence of dementia.
New treatments for Alzheimer’s disease

Solanezumab is a new treatment developed by Lilly, given by a monthly intravenous infusion and which, essentially, dissolves the amyloid plaque, improving symptoms in mild disease by 30%. The definitive trial is out October 2016. Identifying people who would benefit from the treatment is a priority and the least invasive way to detect amyloid is on a scan (below, which currently costs £1400).
What we are trying to do...
Dementia Friends impact

- 71%: As a carer I feel that DF is inspiring communities to make a positive difference to people with dementia
- 61%: I feel more confident interacting with people with dementia
- 77%: I have a better understanding of dementia
- 79%: I feel motivated to do more to help others in my community
Dying well

Specific issues around dementia
• concerns about capacity
• not perceived as a terminal illness
• 30% of those over the age of 60 will die with or from dementia
• 50% will have at least two admissions in their last year of life
• less likely to receive hospice or palliative care
• less likely to have their spiritual needs considered when they die
Clinical issues in EOD

• Atypical forms of Alzheimer’s common
  – Posterior cortical atrophy
  – Biparietal AD
  – Logopaenic aphasia

• Frontotemporal dementia common
  – Behavioural variant
  – Semantic dementia
  – Progressive non-fluent aphasia

• Vascular dementia rare

Thanks to Jeremy Isaacs
Causes of dementia <65

- Alzheimer's disease: 34%
- Vascular dementia: 18%
- Frontotemporal dementia: 12%
- Alcohol-related dementia: 10%
- Dementia with Lewy bodies: 7%
- Huntington's disease: 5%
- Other dementias: 14%

Causes of dementia > 65

- Alzheimer’s disease: 62%
- Vascular dementia: 17%
- Mixed dementia: 10%
- Lewy body dementia: 4%
- Frontotemporal dementia: 2%
- Parkinson’s dementia: 2%
- Other: 3%

Kester M L, Scheltens P Pract Neurol 2009;9:241-251

Dementia UK 2nd edition 2014
Clinical issues in EOD

- Investigating younger patients is (rightly) resource intensive
- MRI preferable to CT in younger people
  - may need repeat imaging
  - subtle changes used to “rule in” diagnoses, not just “rule out” mimics
- Imaging needs to be reported by specialist neuroradiologists
- Standard imaging (CT/MRI) may be normal
- Greater reliance on neuropsychology
- Role for functional and biomarker-based diagnostics e.g. FDG-PET, CSF tau and Abeta

Thanks to Jeremy Isaacs
Clinical issues in EOD

• Genetic forms of dementia commoner in young onset cases
  – Alzheimer’s: PS1, APP, PS2
  – FTD: C9ORF72, MAPT, GRN, VCP
  – Vascular: Notch3 (CADASIL)

• When to test?
• Which genes in which order?
• How to counsel patients and worried relatives who accompany them to clinic?
How do people live well with EOD?

• Spouses do extraordinary things to support the person with the condition
  – Bring the resourcefulness of their generation to the situation
• But evidence suggests that carer burden in EOD is at least as high as in late onset dementia
• Young adult children often heavily involved
• Emergence of BPSD can precipitate a crisis
• Some options for personal home care exist
• Residential care options are extremely limited

Thanks to Jeremy Isaacs
Do we need EOD hubs?

- Incidence and prevalence of EOD in individual boroughs/CCGs may be too low to create clinically viable dedicated services
  - Younger people seen alongside older people by memory clinics and social care

- No systematic evidence that memory clinics don’t offer a good service to younger patients
  - But in general you get good at something you do regularly

Thanks to Jeremy Isaacs
Younger onset dementia

Define what it is – partly the numbers, adults of working age

Consider the clinical need – well described, person centred care, awareness, networks

Articulate the issue - the Wellbeing Pathway

Position the challenge – 100,000 genomes

Link with other groups eg LD, BME groups
Alistair.burns@nhs.net

07900 715549