Dementia diagnosis – role of memory services

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timely diagnosis?

Figure 1: Timeline of disease progression

- **Onset of neuropathology**
- **Reliably predictive biomarkers**
- **Onset of cognitive decline**
- **Onset of disability**
- **Subjective impairment/helpseeking**

**T1** Earliest possible diagnosis in the event that we develop reliably predictive biomarkers

**T2** Earliest possible diagnosis using currently available technology

**T3** ‘Timely’ diagnosis, responding to patient and carer concerns rather than proactively screening for the disease

**T4** Current ‘late-stage’ diagnosis

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Where are we in diagnostics?

- A simple quick diagnostic test that tells us if we have dementia  
  
- A simple efficient screening test that would work in populations to identify those with high likelihood of dementia  
  
- Accurate diagnosis by careful clinical assessment with multi-disciplinary synthesis of history, examination and investigation  
  
- Tests to help make decisions about diagnosis and sub-diagnosis  
  
- Tests to make that diagnosis for us  

BE WARY OF THE DIFFERENCE BETWEEN RESEARCH AND PRACTICE
Rates of dementia diagnosis across the UK

alzheimers.org.uk/dementiamap
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Why inaction?

- Onset insidious
- Lack of insight
- No simple test
- Stigma

- Public misconceptions
- Professional misconceptions
- Role uncertainty

- Impaired help seeking
- Impaired help offering

Inaction
OK, but why bother trying to change this?

- What are the benefits of diagnosis of dementia?
- What are the harms of diagnosis of dementia?
- What are the benefits of early diagnosis?
- What are the harms of early diagnosis?
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Gunter Sachs Commits Suicide, Alludes to Alzheimer's Struggle in Note

May 10, 2011
By KATIE MOISSE via GOOD MORNING AMERICA

The death of Gunter Sachs, iconic playboy of the go-go 1960s, has brought to light how depression often accompanies Alzheimer's and other neurodegenerative diseases such as Parkinson's and Huntington's. The German billionaire and ex-husband of Brigitte Bardot fatally shot himself Saturday at his chalet in Gstaad, Switzerland, at age 78, leaving a suicide note that revealed his struggle with an illness he dubbed "A," thought to stand in for Alzheimer's.
Services for early diagnosis and intervention in dementia for all – markers of quality

- Working for the whole population of people with dementia
  - ie has the capacity to see all new cases of dementia in their population

- Working in a way that is complementary to existing services
  - About doing work that is not being done by anybody

- Service content
  - Make diagnosis well
  - Break diagnosis well
  - Provide immediate support and care immediately from diagnosis

Banerjee et al 2007, IJGP
What is diagnosis for? Production of health and wellbeing in dementia

- How we turn people with worrying symptoms into people who know what is going on
- How we turn toxic uncertainty into empowered understanding
- How we enable choice, self-efficacy and quality of life and quality of care

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"scientia potestas est" Meditationes Sacrae (1597)

• Francis Bacon  
  – 1561 to 1626

• Founder of empiricism and the scientific method

knowledge is power
Changes over time in real world clinical practice, DEMQOL scores from the Croydon Memory Service

- routine practice
- data from patients remaining in service
- baseline, 6 months and 12 months
- indication of the possibility of change
- one element of responsiveness
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Dementia care pathway – simple, navigable and commissionable

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

Help seeking

primary care

social care

DIAGNOSIS specialist role

social care community & care homes

Acute trusts

specialist older people’s mental health services

primary care

Peer & voluntary Sector support

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“The future is unwritten”
Joe Strummer