NICE Dementia Guideline and implications for learning disability

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Context for us today

- People with LD are living longer
- There’s an increased rate of dementia in LD generally
- Special case of Down’s syndrome & Alzheimer’s
- There are treatments
- MMSE not appropriate for LD population
- Neuroimaging may be confusing & unhelpful
- Nevertheless significant research & consensus about diagnosis in LD population
Equity issues

• Nonsense such as “the drugs aren’t licenced for people with Down’s syndrome/LD”
Donepezil, galantamine, rivastigmine (review) and memantine for the treatment of Alzheimer’s disease

This guidance constitutes a review of NICE technology appraisal guidance 111 on the use of donepezil, galantamine and rivastigmine for the treatment of mild to moderately severe Alzheimer’s disease, published in 2001, and a new appraisal of the clinical and cost effectiveness of memantine for moderately severe to severe Alzheimer’s disease.

1 Guidance

This guidance applies to donepezil, galantamine, rivastigmine and memantine within the marketing authorisations held for each drug at the time of this appraisal. That is:
- donepezil, galantamine, rivastigmine for mild to
  moderately severe Alzheimer’s disease
- memantine for moderately severe to severe Alzheimer’s disease.

The benefits of these drugs for patients with either forms of dementia (for example, vascular dementia or dementia with Lewy bodies) have not been assessed in this guidance.

1.1 The three acetylcholinesterase inhibitors donepezil, galantamine and rivastigmine are recommended as options in the management of people with Alzheimer’s disease of moderate severity only if that is, those with a Mini-Mental State Examination (MMSE) score of between 10 and 20 points, and under the following conditions:
- Only specialists in the care of people with dementia that is, psychiatrists including those specialising in learning disability, neurologists, and physicians specialising in the care of the elderly should initiate treatment.
- Cessation of the patient’s condition at baseline should be sought.

1.2 When the decision has been made to prescribe an acetylcholinesterase inhibitor, it is recommended that therapy should be initiated with a drug with the lowest acetylcholinesterase inhibition (MME) score that gives daily dose and the price per dose at the lower levels (MMSE score). However, an alternative acetylcholinesterase inhibitor could be prescribed where it is considered appropriate having regard to other factors that take into account the individual patient’s circumstances and preferences. The benefits of drug interactions and dosing profiles.

1.3 Memantine is not recommended as a treatment option for people with moderately severe to severe Alzheimer’s disease except as part of well designed clinical studies.
Context

- NICE covers England & Wales
- This was joint collaboration of NICE & SCIE
- Outsourced work to NCCMH
History

- HTA vs Guideline
- Preciously only HTA guidance issued 2001
  - Could be interpreted as discriminatory
- New Guideline proposed
  - But original scoping document excluded people with LD
  - Some discussion at stakeholder’s meeting…
  - Eventually LD included
Guideline Development Group

- People who diagnosed & treated dementia
- Social care, psychology researchers & practitioners
- Service users & carers
- However
  - Work on use of drugs for Alzheimer’s outsourced to HTA group, which included none of the above
Firstly, let’s just talk about the Guidelines
General picture
LD specific areas
Key priorities for implementation

• Non-discrimination
  – People with dementia should not be excluded from any services because of their diagnosis, age (whether designated too young or too old) or coexisting learning disabilities.
People with a learning disability

• Health and social care staff working in care environments where younger people are at risk of developing dementia, such as those catering for people with learning disabilities, should be trained in dementia awareness.

• People with learning disabilities and those supporting them should have access to specialist advice and support regarding dementia.
Liaison (1)

• Managers of local mental health and learning disability services should set up consultation and communication channels for care homes and other services for people with dementia and their carers.
Liaison (2)

- Liaison teams from local mental health and learning disability services should offer regular consultation and training for healthcare professionals in acute hospitals who provide care for people with dementia.
- This should be planned by the acute hospital trust in conjunction with mental health, social care and learning disability services.
Liaison (3)

• Those undertaking health checks as part of health facilitation for people with learning disabilities should be aware of the increased risk of dementia in this group.
Who treats?

- Only specialists in the care of people with dementia (that is, psychiatrists including those specialising in learning disability, neurologists, and physicians specialising in the care of the elderly) should initiate treatment.
- Carers’ views on the patient’s condition at baseline should be sought.
Use of drugs?

- Healthcare professionals should not rely on the MMSE score in certain circumstances. These are:
  - in those with an MMSE score greater than 20, who have moderate dementia as judged by significant impairments in functional ability and personal and social function compared with premorbid ability
  - in those with an MMSE score less than 10 because of a low premorbid attainment or ability or linguistic difficulties, who have moderate dementia as judged by an assessment tool sensitive to their level of competence
  - *in people with learning disabilities*
  - in people who are not fluent in spoken English or in the language in which the MMSE is applied.
Assessment in LD

- For people with learning disabilities, tools used to assess the severity of dementia should be sensitive to their level of competence.
- Options include:
  - Cambridge Cognitive Examination (CAMCOG)
  - Modified Cambridge Examination for Mental Disorders of the Elderly (CAMDEX)
  - DMR
  - Dementia Scale for Down Syndrome (DSDS), which can be useful in diagnosis of dementia in people with learning disabilities who do not have Down’s syndrome.
Assessment in learning disabilities and dementia
Assessment (1)

- Multi-stage process.
- Firstly, carers may note deterioration in functioning, or else deterioration is noted as a result of screening the population at risk.
Assessment (2)

- Secondly, investigate & exclude alternative diagnoses in a systematic way.
  - Check vision, hearing and mobility
    - Appropriate tests e.g. Cardiff Acuity Test
  - General health screening including thyroid function tests
  - Consider stress, recent life events, bereavement, intercurrent mental health problem.
Assessment (3)

- No other causes identified, or problems identified & treated but still cause for concern, carry out more specific dementia assessment tests such as the DSDS, DMR and BPT;
- where dementia is diagnosed, the progress of the condition may continue to be monitored using DSDS and BPT.
- May use AMPS at time of diagnosis as part of development of care plan.
**Strutural imaging for diagnosis**

- Structural imaging should be used… to exclude other cerebral pathologies and to help establish the subtype diagnosis.
- MRI is preferred to assist with early diagnosis and detect subcortical vascular changes, although computed tomography (CT) scanning could be used.
- *Specialist advice should be taken when interpreting scans in people with learning disabilities.*
Health and social care staff ...

...working in care environments where younger people are at risk of developing dementia, such as those catering for people with learning disabilities, should be trained in dementia awareness.
People with learning disabilities...

...and those supporting them should have access to specialist advice and support regarding dementia.
Support

- People with learning disabilities should be told their diagnosis of dementia; those supporting them should have access to specialist clinical advice and support about information sharing.
Liaison teams from local mental health and learning disability services...

...should offer regular consultation and training for healthcare professionals in acute hospitals who provide care for people with dementia. This should be planned by the acute hospital trust in conjunction with mental health, social care and learning disability services.
About the drugs...
HTA guidance

• Cholinesterase inhibitors recommended for Alzheimer’s disease of moderate severity (MMSE of 10-20 points)
• Memantine not recommended
So who was on the HTA committee?
Medical members

• NHS Consultants
  – Radiology
  – Nephrology
  – General surgery
  – Diabetes
  – Neonatal paediatrics
  – Cardiology
Other Medical members

3 GPs (2 academic)
2 academic clinical pharmacologists
   one very eminent in cardiovascular disease
   neither with publications in dementia
1 academic psychiatrist specialising in epidemiology
   no publications in dementia
2 academics in public health
   one described on his website as interested in “horizon scanning”
   Neither have publications in dementia
1 SHA medical director
1 specialist in “clinical risk management”
Other Clinical Professionals

- Psychologist specialising in pain control
- Clinical Nurse Specialist in Anaesthetics
Lay members

- 1 with track record of voluntary sector involvement in lupus arthritis, and with National Eczema Society, also member of lay advisory panel for College of Optometrists
- 1 no details
- 1 freelance health researcher who has worked with Food Standards Agency in the past
• 3 health economists
  – none with publications in dementia
• NHS managers
  – 1 finance director
  – 1 CEO of a Welsh Health Board
  – 1 other manager
• Other
  – “Head of HTA Strategy, Eli Lilly & Co”
So how did the HTA come to conclusions about Alzheimer drugs?

- Outsourced data analysis to Southampton Health Technology Assessment Centre (SHTAC), University of Southampton
- Model not in public domain
- Not peer-reviewed
- NICE have refused to publish model
- Not clear to what extent social care costs were taken into account...

.....bearing in mind NICE’s mandate to assess cost effectiveness to the NHS
Southampton study overall findings were published

“Cost-effectiveness analysis undertaken in the present review suggests that donepezil treatment has a cost per quality-adjusted life-year (QALY) in excess of £80,000, with donepezil treatment reducing the mean time spent in full-time care (delays progression of AD) by 1.42–1.59 months (over a 5-year period); cost savings associated with this reduction do not offset the cost of treatment sufficiently to bring estimated cost-effectiveness to levels generally considered acceptable by NHS policy makers.”

• etc…
But...
Acetylcholinesterase inhibitors

- Consider an acetylcholinesterase inhibitor for:
  - people with DLB who have non-cognitive symptoms causing significant distress or leading to behaviour that challenges
  - people with mild, moderate or severe Alzheimer’s disease who have non-cognitive symptoms and/or behaviour that challenges causing significant distress or potential harm to the individual if:
    - a non-pharmacological approach is inappropriate or has been ineffective, and
    - antipsychotic drugs are inappropriate or have been ineffective.

- Do not use acetylcholinesterase inhibitors for non-cognitive symptoms or behaviour that challenges in vascular dementia except as part of properly constructed clinical studies.
Some Implications of HTA Guidance overall

• Worry that may impact on development of memory clinics
• May disincentivise early recognition & treatment
• Unless strong local advocates
Implications of HTA guidance for LD
Remember...

• Healthcare professionals should not rely on the MMSE score in certain circumstances. These are
  – *in people with learning disabilities*
Just mention in passing

- RCPsych/BGS guidance
  - Doctors’ first duty is to their patients, according to GMC
  - Not to NICE, or their employer
  - Where there’s a clash of interest, duty to patients trumps the rest
- For some reason the neurologists didn’t sign up to it
& judicial review...
Summary

• Lots of opportunities for LD services
  – Develop services equitably
  – Use medication flexibly (except memantine)