

Outcomes for people with intellectual disabilities and dementia

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Learning Disabilities
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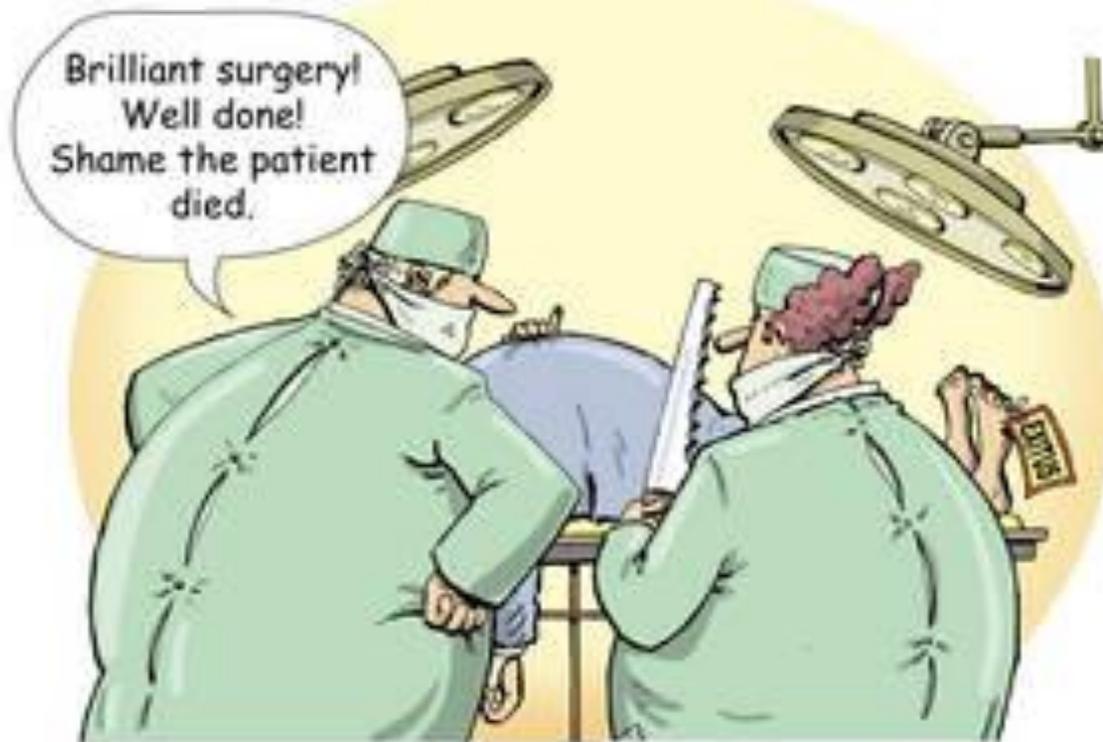
What do we mean by outcomes?



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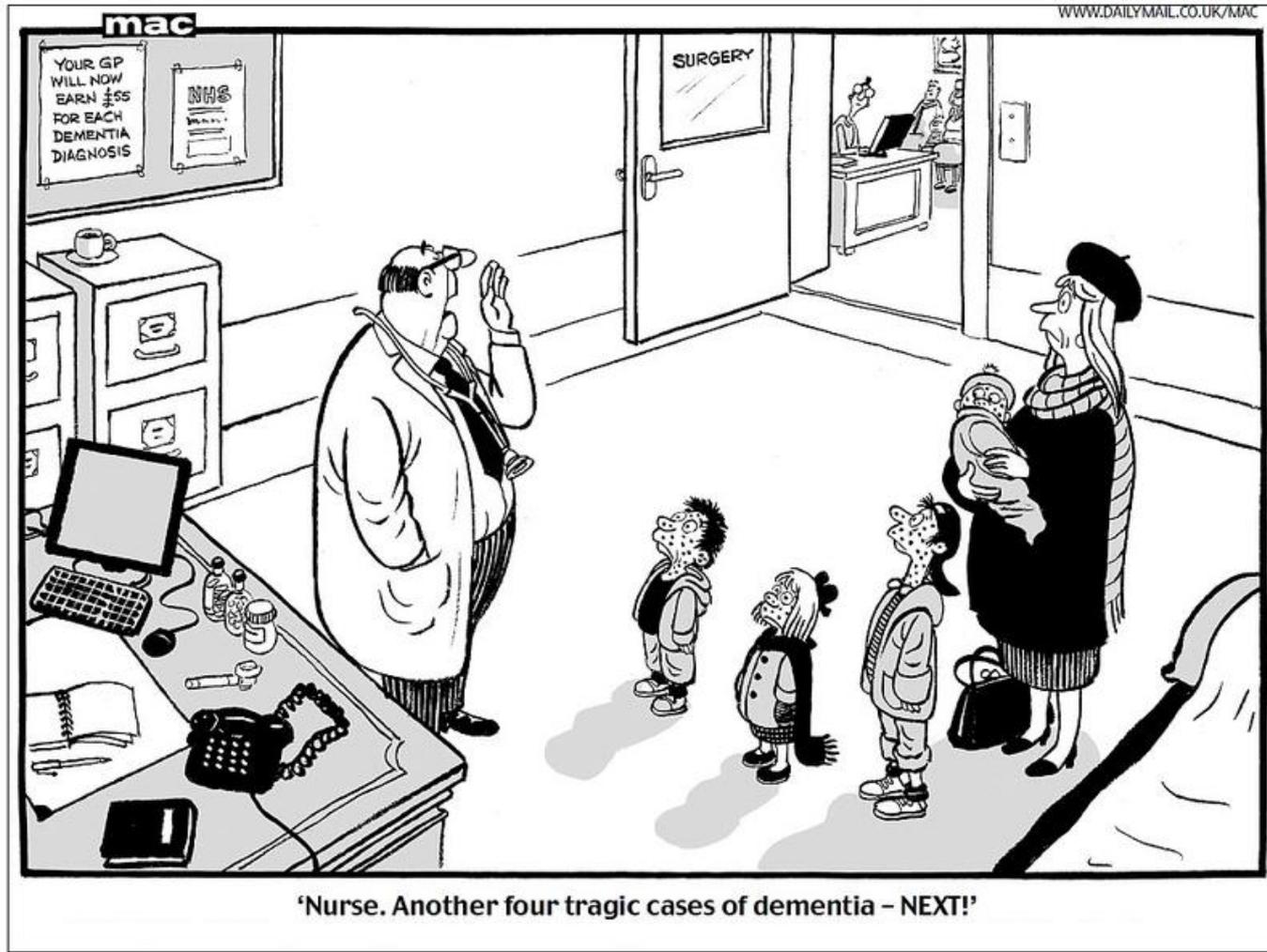


Do outcomes matter?









'Nurse. Another four tragic cases of dementia - NEXT!'



Working to become
**Dementia
Friendly**
2014-2015



What outcome?

What are we talking about?

- Outcomes for a whole area?
- Outcomes for a service?
- Outcomes for an individual with learning disabilities and dementia?

Definition:

‘a measure of the quality of care, the standard against which the end result of the intervention is assessed.’

- **What are the standards that we are trying to achieve?**
- **How do we know what we are doing is meeting these standards and delivering Quality Outcomes across services and for individuals?**

NICE Quality Standards

Two quality standards (QS1 NICE, 2010, QS30 NICE, 2013) which define what constitutes a high standard of care for people with dementia for people in England and Wales.

- Covers care provided by health and social care staff in direct contact with people with dementia in all settings
- Requires that dementia services should be integrated approach to commissioning and provision of services encompassing the whole dementia care pathway.
- Provides clinicians, managers and service users with a description of what a high-quality dementia service should look like. It describes markers of high-quality, cost effective care that, when delivered collectively, should contribute to improving the effectiveness, safety, experience and care for adults with dementia

QS30

- NICE dementia quality standard QS30 (NICE, 2013) covers supporting people to live well with dementia.
- This set of standards applies to all social care settings and services working with and caring for people with dementia.

Issues with the Quality Standards

- Unfortunately both these quality standards have been written as inputs rather than outcomes
- The measures for assessing compliance with these quality standards are purely quantitative in nature
- Desired levels of achievement should be defined locally.

Self Assessment Checklist

- In our original guidance on dementia (BPS, 2009) a self-assessment checklist with 15 standards was developed that can be used to evaluate the provision of dementia care across health, social care and voluntary agencies in a geographical area.
- Many areas have used this as a basis of developing their local dementia strategy for people with intellectual disabilities and to benchmark their services and develop an action plan (e.g. Surrey Learning Disabilities & Dementia Strategy 2011).

Current Standards

1. Legal framework & guidance
2. Population
3. Multi-agency dementia strategy
4. Care Pathway
5. Multidisciplinary approach to assessment, diagnosis and support
6. Assessment & diagnosis
7. Person Centred Dementia Care
8. Care management & review
9. Interventions
10. Dementia friendly environments
11. 'Dying in Place'
12. Choices and rights of people with learning disabilities and dementia
13. Support to family carers
14. Capable workforce
15. End of Life Care
16. Outcomes



How are they being used?

- Measuring the practice of specific teams on selected standards:
 - Residential and nursing homes.
 - Clinical teams that provide assessment & treatment.

- City / County-wide strategy (e.g. Sheffield, Surrey)
 - Stocktake of current services across the city.
 - Identify our strengths and gaps.
 - Develop strategic plan.

Making it Happen across services

- Agree where to start
- Depends on where you are in the system e.g. CTPLD, service provider, commissioner
- Working together
- Constantly develop and improve
- Measuring outcomes

Dementia strategy

Standard

- Each geographical area has an agreed multi-agency learning disabilities and dementia strategy for people with learning disabilities with an agreed action plan that addresses the standards outlined in this document.

Issues

- Which agencies are involved in development?
- Is this separate to a mainstream dementia strategy?
- Who signs it off?
- How is it resourced, implemented and monitored?
- Commissioning intentions



Database

Standard

- Each area has a register / database of people with learning disabilities, which identifies people with Down's Syndrome that can be used to plan and deliver effective services.



Database

Issues

- Is there already a comprehensive register that identifies people with Down's syndrome both who originate from the area?
- Is there a register of people with Down's syndrome who originate from elsewhere but are placed within your area?
- How is the database kept up to date – both re new people and people who have died?
- What information are you going to collect?
- How easy will it be to keep up to date?
- Do you also keep a 'deaths database'? How do you get accurate data on cause of death?

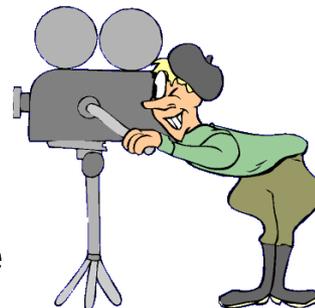
Assessment

Standard

- ▶ People who develop, or are at risk of developing dementia have easy access to comprehensive assessment and diagnostic services according to an agreed protocol.

Issues re assessment

- Services need to decide what they are offering:
 - baseline, reactive screening, and / or prospective screening
- Has prospective screening been overtaken by Annual Health checks?
- Choice of assessments
 - appropriateness for range of LD
 - suitable as dementia progresses
 - floor / ceiling effects
 - reliability and validity
- Collecting other information
e.g. video / documentation
- Longevity of assessment choice



Care Management & review

Standard

- People who develop, or are at risk of developing dementia have their care purchased, monitored and reviewed by an effective care management system, whether in the geographical area or in an out of area placement.

Issues

- Having a named care manager.
- Regular care reviews.
- Access to flexible funding to meet changing needs without delay.
- Outcomes monitored regarding their quality of life.
- Staffing levels increased as needed including waking night staff.
- Issues re moves.
- No multiple moves.

Interventions

Standard

- People who develop dementia have prompt access to the full range of medical, psychological, therapeutic and social interventions as required.

Issues

- Is there an agreed protocol for use of medications?
- Is there access to the full range of therapy professionals and equipment?
- Services ability to recognise and provide the therapeutic and social input needed.
- Understanding the impact of dementia on short term and roll back memory.
- Failure-free activities



Dementia Friendly Environments

Standard

- People who develop, or are at risk of developing dementia, have accommodation and day and leisure activities which are dementia friendly and are commissioned to meet their changing needs.

Issues

- Is there an audit of provision to see if it is dementia friendly?
- How have mainstream or ID services been adapted for people with dementia?
- Provision of suitable equipment.



Quality Outcome Measure for Individuals with dementia (QOMID)

We wanted to develop a quality outcome measure that could look at the quality of care that the person is receiving.

We wanted it to be:

- Used with anyone with dementia
- Was stage specific
- Gave a clear definition of what needed to be achieved
- Could be used to help both evaluate quality outcomes and plan to improve it

QOMID meets the recommendations for the outcomes framework reviewed by Janicki (2011)

Describing the QOMID

QOMID is Quality Outcome Measure for Individuals with Dementia.

- consists of 17 domains which explore the key areas that ensure that the person with dementia is experiencing a good quality outcomes
- staged for the three main stages of dementia – suspected/ early; mid and late stage.
- although the domains are the same for each stage, the description of quality outcome may change across the stages to reflect the different requirements as dementia progresses.
- Available at http://dcp-ld.bps.org.uk/dcp-ld/useful-links-and-info/useful-links-and-info_home.cfm

Domains

1. Person Centred Approaches to Support
2. Positive Risk taking
3. Respect for Human Rights
4. Consistency of approach
5. Interaction with others
6. Emotional reassurance to cope with changes
7. Orientation
8. Daily Living
9. Carrying out preferred activities
10. Flexibility of support
11. Environment
12. Behaviour
13. Health
14. Support from well co-ordinated agencies
15. Nutrition
16. Mobility
17. Continence



AREA	SUSPECTED / EARLY STAGE DEMENTIA	MID STAGE DEMENTIA	LATE STAGE DEMENTIA
<p>7. ORIENTATION</p>	<p>The person is oriented to time and place through approaches that are appropriate to their level of ability. Their support plan describes routines that are likely to be important to the person as the dementia progresses.</p> <p>There is evidence that the team has made plans to ensure that any future changes that are envisaged for the person are properly considered and take account of possible effect on the person's orientation</p>	<p>The person is able to understand their daily routine through the use of appropriate cues and aids e.g. daily picture timetable, picture menus, picture staff rotas.</p> <p>There is evidence that the team has made plans to ensure that any future changes that are envisaged for the person are properly considered and take account of possible effect on the person's orientation</p>	<p>The person feels safe in having a consistent and familiar routine.</p>



Forward planning

- The QOMID is designed to help the support team and the professionals to work with the person to both prevent deterioration in quality and to forward plan effective care.
- For each domain that is scored at less than 4, the support team is asked to specify what needs to be put in place to improve the person's quality outcome for that domain.
- These actions can then be included in the person's support plan.
- In addition, by looking at the descriptions for the next stage of dementia, the professional can begin to help the person and their supporters to think about what needs to be put in place to maintain their quality outcome.

Mid Stage Scenario

- James is a 58 year old man with Down's syndrome and in mid stage dementia. He lives in a 6 bedded LD residential home in a complex of 4 homes, which have been through difficult times. It is now more stable and the manager of the complex has now decided that this home will become a specialist LD & dementia home.
- Undertook the QOMID with staff, family and James in March 2013
- Overall score was 57 – good quality outcome

Identified areas of need

	Domain	Score	Actions required
1.	Person Centred Approaches to Support	3	Life Story Book needs to be done – assistant psychologist, family and staff
4.	Consistency of approach	3	Guidelines for morning and evening routine need to be put on the inside of James' wardrobe door, and all staff informed.
7.	Orientation	2	More picture cues are needed. Larger staff picture board, daily timetable, picture menu, pictures for events /shopping
9.	Carrying out preferred activities	3	Further favourite activities have been identified from James' earlier years with family. Brother to make James a Shovehappy board. Outings to Bognor / Wittering. Putting green – Littlehampton. Putting set for garden

	Domain	Score	Actions needed
11.	Environment	2	Some work has started but a fuller programme of environmental modifications is needed e.g. red toilet seats, more signage etc
13.	Health	3	DisDAT to be completed re non verbal ways of assessing distress for James. More attention to be paid to need for Vitamin D and DH guidance
16.	Mobility	3	Shoes need to be checked regularly for fit, and staff to check walking regularly
17.	Contenance	2	Mattress on bed needs to be sorted Pads need to be sorted – pull ups during the day and flexitab at night Staff to ensure bedtime routine is followed. Toileting programme and monitoring chart to be started asap Community Nurse to follow-up re continence products and funding

How is it being used?

- Part of assessment and review process in both Surrey and Cornwall
- Milestones Trust now looking at using it in their mainstream dementia as well as ID dementia services
- Being endorsed by KSS Academic Health Sciences Network
- Article accepted for publication

Any Questions?



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