

Dementia: The Ups and Downs

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Surrey Heath Partnership Board

Declaration of Interests

- **NHS:**
 - GP East Surrey
 - SCN SE Clinical Lead Dementia
 - Co-developer of MoodHive (Depression Anxiety Pathway)
- **Royal College of General Practitioners**
 - Clinical Lead Dementia
 - Co-Chair Learning Disability Special Interest Group
 - Member Dementia Roadmap Steering group
- **Consultancy / Advisory Boards / Speakers Bureau:**
 - Alz Soc, Cerestim Ltd, Chase Pharmaceuticals, Cyttox, Edmund de Rothschild, Eli Lilly, Lundbeck, Otsuka, Pfizer, Pri-Med, Roche, Servier, Wellcome Trust
 - psi-napse



Dementia Diagnosis in People with a Learning Disability - Questions

- **Do you know what signs and symptoms are suggestive of dementia in people with learning disability?**
- **Do people ask routinely about symptoms suggestive of dementia in people with learning disability?**
- **Do you have a specified service to review / assess concerns about dementia in people with learning disability?**
- **If not – how would you refer someone with learning disability if you had concerns about the possibility of dementia?**



Overview

- **Dementia in the South Region**
 - Where we are now / What we still need to do
- **Dementia in People with Learning Disability**
 - The Issues
 - Recognition
 - Assessment
 - Management
 - Commissioning Implications



Dementia Diagnosis vs Standard

National Rates

- Mar 2015: 61.6%
- Mar 2016: 67.5%

Diagnosis Rates by Region Mar16

- North: 72.3%
- Midlands: 65.3%
- London: 72.2%
- South: 63.8%

Diagnosis Rates South Region Mar16

- South Central: 65.5%
- South East: 63.8%
- South West: 61.7%
- Wessex: 64.7%



Dementia Diagnosis vs Standard

- **The overall figure for the South 63.8% is a small ↑ of 0.6 % points since Dec 15**
 - **Below standard by 3.2% points.**
- **Surrey Heath:**
 - **Reached 65% Nov 16**
 - **Achieved 65.1% Mar 16**
- **Important to:**
 - **Understand Dementia Register Dynamics**
 - **Attrition, MAS, Care Homes**
 - **Have a strategy for Care Plans for people with LT conditions; especially review of such pts in Care Homes**
 - **Involve wider Primary Care Team**
 - **Review Dementia Register in Primary Care e.g. MDT meetings**



Dementia Recognition

- **Collection of monthly dementia diagnosis QOF data is subject to a direction, and therefore mandatory**
- **We are doing better BUT room for improvement**
- **Sustainability and Transformation Plans 2016-21**
 - **One question under the Care & Quality section for the “five year plan” is How dementia services will be improved?**

If Dementia Diagnosis Rates are to be Achieved and Maintained the Recognition of people “at risk of” and “with dementia” needs to be

- **An ongoing process:**
- **Embedded in every day practice throughout Health and Social Care**



Dementia in People with Learning Disability



Dementia in People with Learning Disability

- **Due to advances in medicine People with a Learning Disability are living longer**
 - Understanding the effects of ageing ↑ important
- **People with learning disabilities:**
 - Have an ↑ risk of developing dementia as they age
 - Are at greater risk of developing dementia at a younger age – particularly those with Down's syndrome
- **Dementia generally affects people with learning disabilities in similar ways to people without a learning disability, but there are some important differences.**



Dementia in People with Learning Disability

- **Are less likely to:**
 - Receive a correct or early diagnosis of dementia
 - Be able to understand the diagnosis
- **May experience more rapid progression of dementia**
- **May already be in a supported living environment**
 - Already have help to allow them to live independently
- **May have already learnt different ways to communicate**
 - eg more non-verbal communication if disability affects speech
- **Will require specific support to:**
 - Understand the changes they are experiencing
 - Access appropriate services after diagnosis & as dementia progresses



Dementia in People with Learning Disability: Downs and Non-Downs

- **Downs**
 - **Usually due to Alzheimer's disease**
 - **Trisomy chromosome 21 linked to ↑ amyloid production (basis of plaques)**
 - **Growing awareness can develop other forms of dementia.**
 - **Incidence:**
 - **1 in 50 people aged 30 to 39 yrs**
 - **1 in 10 people aged 40 to 49 yrs**
 - **1 in 3 people aged 50 to 59 yrs**
 - **Over 50% when aged 60 yrs or more**
- **Non-Downs**
 - **Dementia 3-4 times higher than the general population**
 - **1 in 10 people aged 50 to 65 yrs**
 - **1 in 7 people aged 65 to 75 yrs**
 - **1 in 4 people aged 75 to 85**



Dementia in People with Learning Disability: Comparative Prevalence

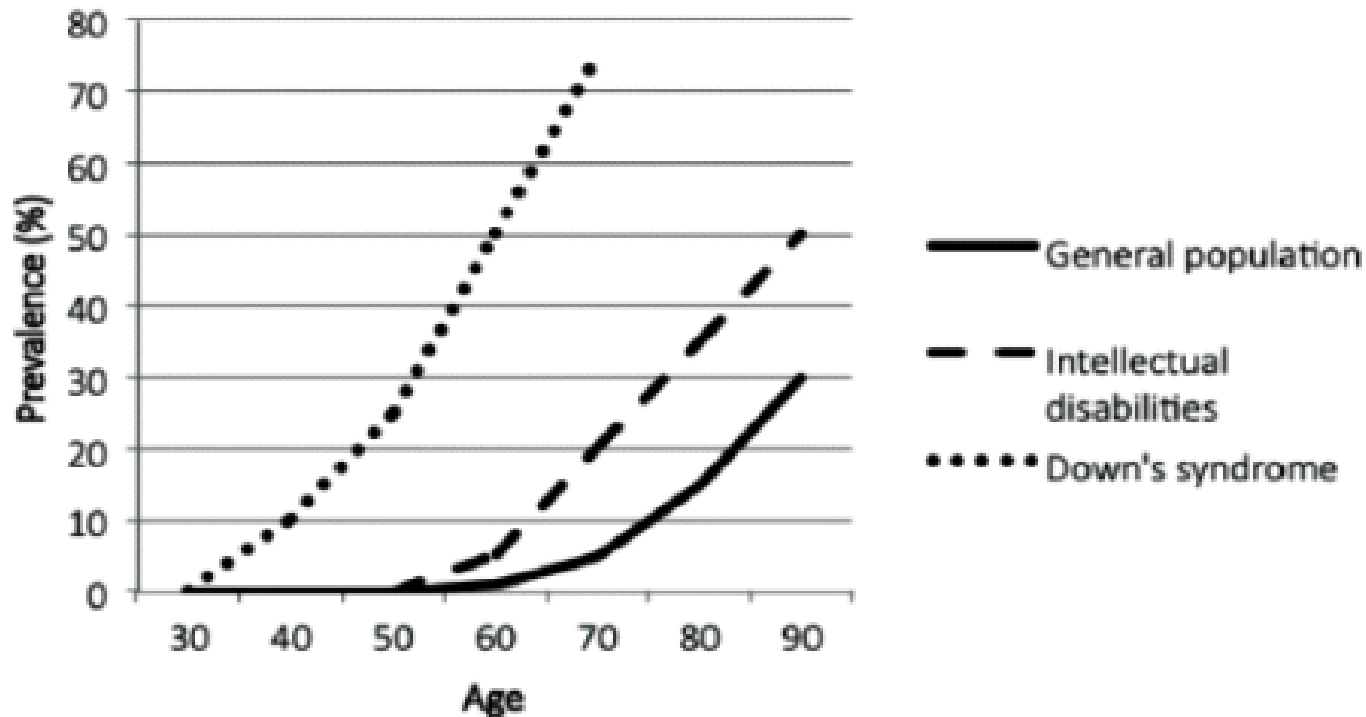


Figure 1: Comparison of dementia prevalence rates by age

Ref: Strydom 2014



Dementia in People with Learning Disability: Downs and Non-Downs

- **Downs:**
 - Often show symptoms other than memory impairment in the early stages of dementia. Changes in:
 - Behaviour, personality - more stubborn, irritable, withdrawn
 - Decline in daily living skills e.g. continence, personal hygiene,
 - ↓ Co-ordination of gait, depth perception problems
- **Non-Downs**
 - **Mild Learning disability:**
 - Dementia similar to dementia in the general population
 - Symptoms, rate of progress
 - **Severe Learning disability:**
 - Initial symptoms often less typical
 - Changes in personality or behaviour



Dementia in People with Learning Disability: Downs and Non-Downs

- **History Information Gathering:**
 - Nature of presenting problem(s), origin, rate/pattern of progress (sudden/gradual)
 - Presence of seizures and other associated conditions
 - Impact on functioning / personality.
 - History of significant physical and medical history;
 - Diabetes, hypertension, thyroid, CVD, B12 deficiency.
 - History of or current psychiatric symptoms:
 - Depression, anxiety or other mental health problems.
 - Record developmental history and best level of historic functioning:
 - Previous neuropsychological tests - compare current data
 - Record historic daily living skills, interests/hobbies/skills and details of personality.



Dementia in People with Learning Disability: Downs and Non-Downs

- **History Information Gathering:**
 - **Family history:**
 - **Dementia or other mental health and medical conditions (particularly in first-degree relatives).**
 - **Assess for psychosocial issues, changes or life events.**
 - **These include house moves, health decline/death of loved ones, change of caregivers, changes to, or retirement from work/day services.**
 - **Information gathering should be undertaken through a combination of informant interview (preferably with a family member, when relevant and appropriate) or an informant who has known the person well for a period of six months at least) and directly from the person where possible.**



Dementia in People with Learning Disability: Downs and Non-Downs

- **Physical evaluation; key issues are:**
 - **Cardiovascular system:**
 - Focal deficits, evidence of cardiovascular accident etc.
 - **Detailed neurological examination**
 - Focal deficits, gait abnormalities, speech abnormalities etc.)
 - **Endocrine system: signs of hypothyroidism.**
 - **Careful recording of:**
 - Historic / newly added / current medications
 - Particular attention psychoactive, AED sedating anticholinergic)



Dementia in People with Learning Disability: Downs and Non-Downs

Modified Anticholinergic risk scale

the higher the number the greater the anticholinergic effect and the greater the risk

Category 1	Category 2	Category 3
Haloperidol, quetiapine, mirtazapine, paroxetine, trazodone, ranitidine, lofepramine	Clozapine, notryptiline, olanzapine, baclofen, cetirizine, loratadine, cimetidine, loperamide, prochlorperazine, tolteridone, sertraline	Chlorpromazine, amitryptiline, imipramine, chlorpheniarmine, oxybutynin, hydroxyzine

Ref:nhs Scotland Polypharmacy Guideline Modified Anticholinergic Risk Scale <http://www.sehd.scot.nhs.uk/details.asp?PublicationID=5545>



Dementia in People with Learning Disability: Downs

- **Recommended routine investigations:**
 - Full blood count.
 - Urea & electrolytes.
 - Blood sugar.
 - Thyroid function tests.
 - Liver function tests.
 - B12 and Folate level.
 - Lipid profile.
 - Sensory screening – vision and hearing.
- **Optional tests are:**
 - Electro Encephalograph (EEG)
 - Neuro-imaging
 - Electrocardiograph (ECG)



Dementia in People with Learning Disability: Downs and Non-Downs

- **Assessment tools for dementia in the general population are NOT appropriate for people with intellectual disabilities.**
- **Mental State Evaluation:**
 - **Level of alertness**
 - **Orientation to time, place and person**
 - **Any evidence of alterations in consciousness, psychomotor activity, mood, thoughts, evidence of any abnormal mental beliefs or experiences, and perceptual abnormalities.**
 - **Formal assessment of memory and other cognitive functions**



Dementia in People with Learning Disability: Downs syndrome

- **Neuroimaging:**
 - Most consistent structural change in early stage of Alzheimer's disease is atrophy of the medial temporal lobe.
- **Issues:**
 - **People with Down's syndrome have medial temporal lobe atrophy even without dementia.**
 - Normative values not yet established;
 - Value is mainly to rule out structural lesions other than atrophy (e.g. space occupying lesions).
 - Use only when clinical picture suggests possibility of such lesions.

Neuroimaging has limited value in early diagnosis of Alz Dis in Down's syndrome.



Dementia in People with Learning Disability: Downs syndrome

- **Environmental Assessment:**
 - **Quality of the person's physical environment.**
 - **Staffing levels (day and night).**
 - **The mix of people with intellectual disabilities in the residential and day care settings.**
 - **Quality and quantity of day activities.**
 - **Staff characteristics: attitudes and competence, including consistency of approach.**
 - **Scrutiny/review of historic/current support package.**



Dementia in People with Learning Disability: Downs and Non-Downs

- **Protocol - Surrey & Borders Partnership (SABP)**
 - Main focus on people with Downs Syndrome; Database kept by SABP
 - **Protocol**
 - Baseline screen at aged 30 yrs
 - Meet with person, key-worker / family; usually at home
 - Detailed feedback to GP and family, carers; includes recommendations
 - **Follow-up**
 - Suspected or diagnosed dementia Review 6-12 mth intervals
 - **Purpose**
 - Ensure tracking of their dementia and care plan
 - Help with further diagnosis
 - **NO dementia at present:**
 - Re-referral if concerns person is changing



Dementia in People with Learning Disability: Downs and Non-Downs

- **Need Specialist Assessment**
- **Screening:**
 - **Dementia Questionnaire for People with Learning Disabilities (DLD):**
 - Screening tool for early detection of dementia in adults with LD completed by carers, consists of 50 items..
 - **Dementia Scale for Down's Syndrome (DSDS)**
- **Neuropsychological Assessments**
 - **Neuropsychological Assessment of Dementia in Adults with Intellectual Disabilities (NAID).**
 - Battery of simple tests for memory, orientation, language, praxis.
 - Majority of people with Down's syndrome can attempt most of it
 - Takes about 45 minutes
- **The Glasgow Depression Scale (GDS-LD):**
 - 20-item questionnaire for people with learning disabilities



Dementia in People with Learning Disability: Commissioning

- **What are the elements of a good service?**
- **Commissioners will want to ensure that:**
 - **Demographics are known including having a database of all adults with intellectual disabilities which includes identification of people with Down's syndrome and those in out of area placements.**
 - **There is:**
 - **A multi-agency dementia strategy.**
 - **A multi-agency care pathway for assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia.**
 - **A multi-disciplinary approach to assessment and diagnosis and support**
 - **Prompt access to assessment / diagnostic services including baseline assessment for people with Down's from age 30.**



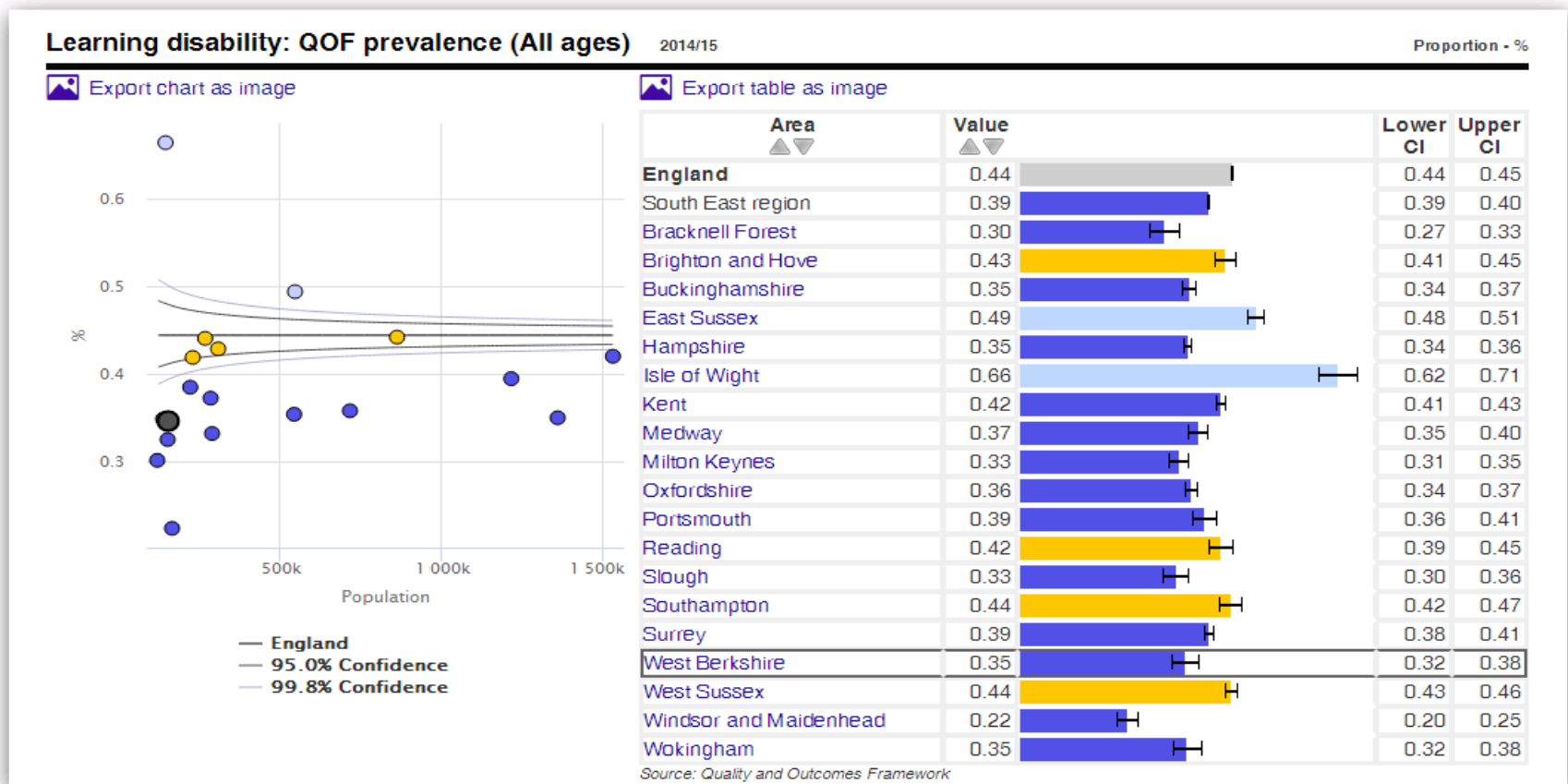
Dementia in People with Learning Disability: Commissioning

- **What are the elements of a good service?**
 - **There is:**
 - **Person-centred dementia care**
 - **Effective care management and review system.**
 - **Prompt access to the full range of medical, psychological, therapeutic and social interventions.**
 - **Dementia friendly living and day service environments**
 - **Ability to support the person to remain in their familiar home with additional supports provided in a timely manner.**
 - **Support available to family carers and service providers.**
 - **A capable trained workforce able to deliver excellence in dementia care.**
 - **End of Life care that follows the requirements of the National End of Life Strategy**



Dementia in People with Learning Disability:Fingertips Tool

Identified Areas of Need



Ref:fingertips.phe.org.uk/profile/learning-disabilities/data#page/0



Dementia in People with Learning Disability: Outcomes

- **Links to NICE quality standards**
- **Outcomes for Services – self assessment tool**
- **Outcomes for Individuals:**
 - **Quality Outcome Measure for Individuals with dementia (QOMID)**



Dementia in People with Learning Disability: Self-assessment Tool

- **Similar approach to ‘Green Light toolkit’ and ‘Challenging Behaviour: a unified approach’**
- **Reflects the content of the Report**
- **Translates the Guidelines into “Standards you should see if the recommendations are being met”**
- **Written as outcomes, not inputs**
- **RAG Rate how well your service is meeting each standard**
Green - Amber - Red
- **Can be used to develop a local Strategy and action plan**



Dementia in People with Learning Disability: Self-assessment Tool 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**



Dementia in People with Learning Disability: Self-assessment Tool

- **How To Use**

- **Identify appropriate stakeholder group**
- **Decide which standards the team will look at**
- **Review meeting:**
 - **What are we doing well that meets the standard?**
 - **What are we not doing that we should?**
- **Overall rating Green – Amber – Red**
- **Actions we need to take to improve**



Dementia in People with Learning Disability: Self-assessment Tool

How To Use

- **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



Dementia in People with Learning Disability: QOMID

- **Tool to measure the quality outcome for an individual with dementia.**
- **Can be used with anyone with dementia**
- **Is stage specific**
- **Gives a clear definition of what needed to be achieved**
- **Can be used to help both evaluate quality outcomes and plan to improve it**



Dementia in People with Learning Disability: QOMID - 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**



Dementia in People with Learning Disability: QOMID

Decide which stage of dementia the person currently falls into, based on current assessment and professional opinion.

Suspected / Early stage

Mid stage

Late Stage

Use the column for that stage of dementia and rate each domain using the following rating scale:

1

2

3

4

This is rarely achieved for this person

This is sometimes achieved for this person

This is mostly achieved for this person

This is completely and consistently achieved for this person

For each domain, circle the rating at this current time. All domains should be completed. If the domain is rated less than 4, specify what needs to happen to improve the person's quality outcome in that area of their life.

AREA	SUSPECTED / EARLY STAGE DEMENTIA	MID STAGE DEMENTIA	LATE STAGE DEMENTIA
1. PERSON CENTRED APPROACHES TO SUPPORT	<p>The person experiences support which is underpinned by planning based on:</p> <ul style="list-style-type: none"> the person's own wishes, their capacity (maximising their decision making wherever possible), their needs and history as shown in their individualised support plan which includes <ul style="list-style-type: none"> their person centred plan, health care plan, communication passport, life story book, advanced directives, and end of life planning. 	<p>The person experiences support which is underpinned by planning based on:</p> <ul style="list-style-type: none"> the person's own wishes, their capacity (maximising their decision making wherever possible), their needs and history as shown in their individualised support plan which includes <ul style="list-style-type: none"> their person centred plan, health care plan, communication passport, life story book, advanced directives, and end of life planning. 	<p>The person experiences support which is underpinned by planning based on:</p> <ul style="list-style-type: none"> the person's own wishes, their capacity (maximising their decision making wherever possible), their needs and history as shown in their individualised support plan which includes <ul style="list-style-type: none"> their person centred plan, health care plan, communication passport, life story book, advanced directives, and end of life planning.
	1 2 3 4	1 2 3 4	1 2 3 4

Ref: Quality Outcome Measure for Individuals with Dementia (QOMID)
Karen Dodd & Alick Bush 2013



Dementia in People with Learning Disability: QOMID Case Study

- **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**



Dementia in People with Learning Disability: QOMID Case Study

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 <u>Shovehappy</u> board. Outings to Bognor / <u>Wittering</u> . Putting green – <u>Littlehampton</u> . Putting set for garden



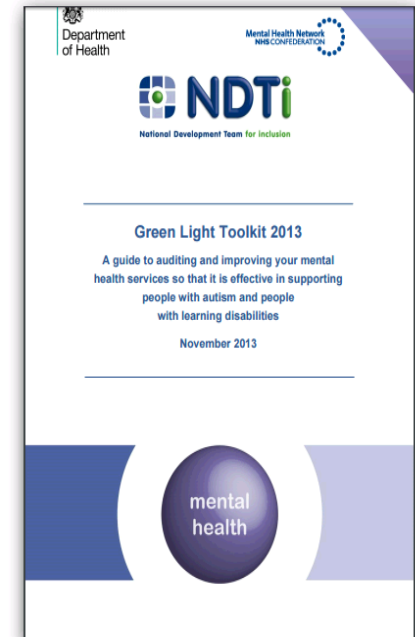
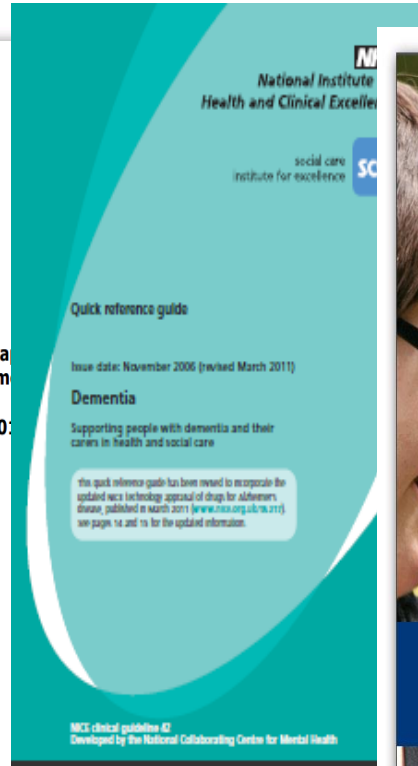
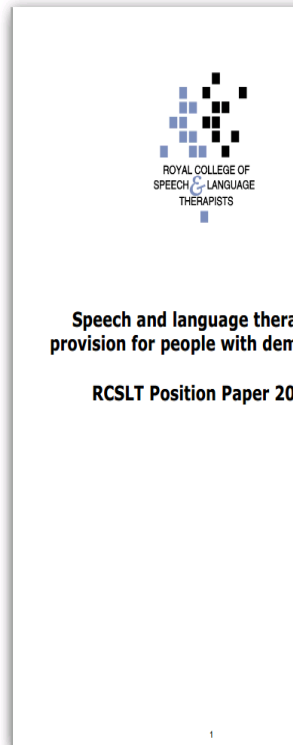
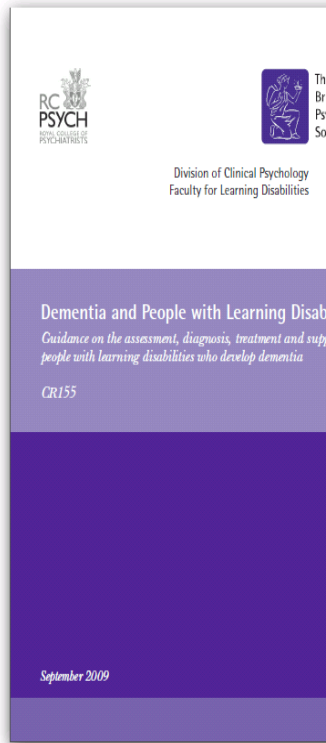
Dementia in People with Learning Disability: QOMID Case Study

Identified Areas of Need

	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	<u>DisDAT</u> 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.	Continence	2	Mattress on bed needs to be sorted Pads need to be sorted – pull ups during the day and <u>flexitab</u> at night Staff to ensure bedtime routine is followed. Toileting programme and monitoring chart to be started <u>asap</u> Community Nurse to follow-up re continence products and funding



Dementia in People with Learning Disability: Useful Documents



Refs: 1. bps.org.uk/system/files/Public%20files/rep77_dementia_and_id.pdf; 2. www.rcslt.org/members/publications/publications2/dementia_position_paper2014. 3. NICE Dementia Guideline; 4. <http://www.rcgp.org.uk/learningdisabilities/~media/Files/CIRC/CIRC-76-80/CIRCA%20StepbyStepGuideforPracticesOctober%202010.aspx>; 5. Greenlight Toolkit www.ndti.org.uk/uploads/files/GreenLight_Toolkit_22_Nov_2013_final.pdf



Dementia Recognition

- We are doing better **BUT** room for improvement
- **Sustainability and Transformation Plans 2016-21**
 - One of the questions under the Care and Quality section for the “five year plan” is How dementia services will be improved?

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Thank you Questions

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