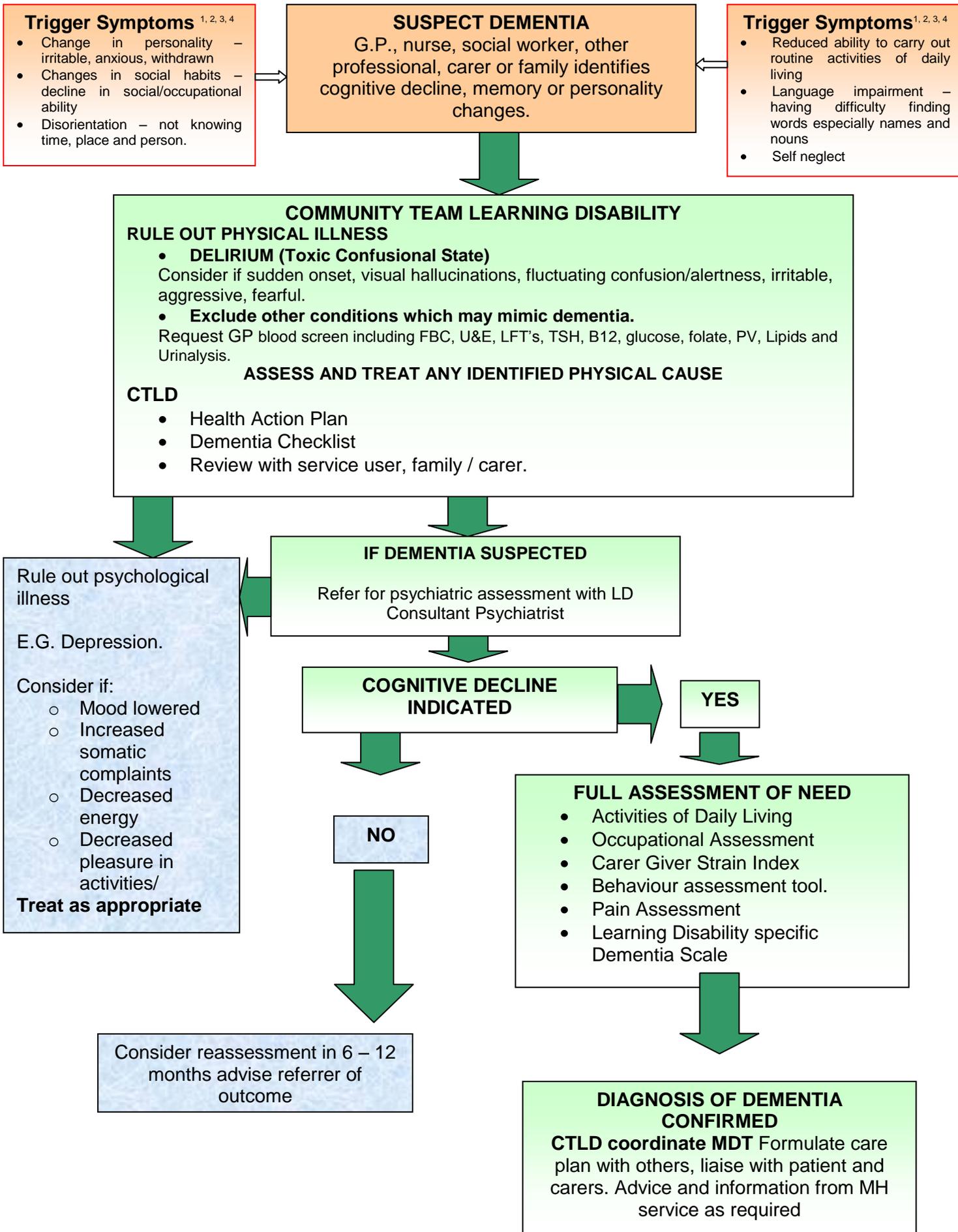


**Rotherham Learning Disability Service Clinical Guidelines for the Identification and Referral of Dementia for People with Learning Disability aged under 65 years**



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**What is Dementia?**<sup>1,2,3,4,5</sup>

- Dementia is a global term used for a group of organic brain diseases affecting normal working functions/processes of the brain leading to a progressive destruction of brain cells
- It is characterised by the development of multiple cognitive deficits, these include memory, orientation, comprehension, learning, thinking, language and judgement to variable extents
- There may be impairment of emotional control and social behaviour and motivation
- There is no clouding of consciousness

**What is Down's Syndrome (DS)**

- DS is a developmental disorder recognisable at birth and is acknowledged as the most common syndrome associated with learning disabilities.
- The life expectancy of people with DS has increased dramatically over the last 50 years and this has highlighted the susceptibility of these patients to dementia of the Alzheimer's type.

**Prevalence and Incidence**

- People with learning Disability (not Down Syndrome) seem to be at a small increased risk of developing dementia compared to those without Learning Disabilities.
- People with Down Syndrome are at a significant increased risk of developing dementia, particularly

**Down's Syndrome and Dementia Prevalence**

Age	Prevalence
30 – 39	2%
40 – 49	9%
50 – 59	36%
60 – 69	66%

Average age of onset is 54 years

Alzheimer's Disease <sup>1</sup>	Vascular Dementia <sup>1</sup>	Dementia with Lewy Bodies <sup>1</sup>
<ul style="list-style-type: none"> <li>• Memory loss with a slow insidious onset</li> <li>• Language impairment</li> <li>• Failure to recognise relations and carers</li> </ul>	<ul style="list-style-type: none"> <li>• Often stepwise progression</li> <li>• Memory loss</li> <li>• Recent stroke, transient ischaemic attack or myocardial infarction</li> <li>• Focal neurological signs</li> </ul>	<ul style="list-style-type: none"> <li>• Fluctuating memory impairment</li> <li>• Prominent visual hallucinations</li> <li>• Repeated falls</li> </ul>

**Diagnosis**

- Mild dementia may be mistaken for normal ageing therefore is difficult to make. Consider early referral for specialist assessment.
- Differential diagnosis is a particular issue for people with Down's syndrome who may be at greater risk of developing hypothyroidism, sensory impairment or experiencing changes in their environment.
- There may be diminution of insight as dementia progresses therefore a history of problems should be sought from a carer as well as the patient.

Health care professionals should be aware of the importance of differentially diagnosing Dementia with Lewy Bodies because of the high risk of increased morbidity and mortality with neuroleptic agents in these patients<sup>1</sup>

**Good practice principles**

- ✓ Need to consider baseline assessments of cognitive and daily living skills of people with Down's Syndrome in early adulthood with ongoing reassessments over time. This would allow concerns to be identified and diagnosis to be considered.
- ✓ Complaints of subjective memory impairment is not a good indicator of dementia but does indicate a problem that merits assessment. Patients who persistently complain of memory problems in the absence of depression, but have normal range cognitive scores should be referred for specialist assessment.
- ✓ In many cases, dementia is associated with other psychiatric symptoms such as depression, anxiety and alcohol related problems. These may be the presenting problems.
- ✓ Sudden onset of confusion or worsening of cognitive functioning should raise a high suspicion of delirium. Delirium and dementia can co exist.
- ✓ Carer giver support can reduce psychological morbidity, delay institutionalisation of the person with dementia and in the longer term be more cost effective in terms of service provision.
- ✓ People with dementia experience common physical symptoms to the same degree as the general population but tend to under report their symptoms.

**Aims and Objectives of Guideline**

- To develop equitable and consistent services for individuals with Down syndrome and Alzheimer's by providing clear guidelines and procedures.
- To promote the individual's quality of life and deliver appropriate, proactive needs led services by facilitating early intervention and diagnosis.

