Learning Disabilities Mortality Review (LeDeR) Programme: Fact Sheet 20

Dementia

Key considerations for reviewers

- Was the person assessed and diagnosed in a timely way, involving their carers, family and friends? Did the diagnosis specify which type of dementia?
- If the person had dementia at the time of their death, was a proactive care plan in place that covered issues that were likely to arise? Did this include timely end of life planning, with efforts to involve the person while they still had capacity?
- Was the person assessed for use of anti-dementia drugs?
- Was the person offered support and treatment enabling them to remain as independent as possible?

Introduction

Prevalence of dementia is higher in people with learning disabilities than those in the general population. Dementia is particularly common in those with Down's syndrome with an early onset and the condition is often more rapid in this group. CIPOLD (2013) found dementia care pathways were often reactive rather than proactive and that health and social care staff didn't always have adequate dementia training. Physical, sensory and mental health needs of people with learning disabilities may go unrecognised and therefore unmet by services, which in turn has negative impacts on the person's quality of life, life chances, life expectancy and experience of services.

Definition

Dementia is a progressive condition that affects mental processes such as memory and problem-solving, as well as mood or behaviour. Common symptoms include difficulty remembering recent events or following conversations, and feeling confused and disoriented even in familiar places.

There are different types of dementia for which symptoms and progression may be different:

- Alzheimer's disease is the most common form of dementia which develops slowly. Early signs include difficulty forming new memories.
- Vascular dementia can occur when blood flow to the brain becomes reduced (e.g. after a stroke). Signs include communication or movement problems, disorientation, memory loss and problems with communication. Vascular dementia can occur with Alzheimer's disease in the same person.
- Lewy Body Dementia - Lewy bodies are tiny deposits of protein in nerve cells. Symptoms can include changes in alertness, hallucinations, fainting and Parkinson's disease type symptoms.
- Frontal Temporal Dementia (Pick's disease) is a rare form of dementia caused by damage to brain cells. Symptoms include lack of personal or social awareness, personality or behaviour changes, and changes in food preference.

Key Principles

Some people with learning disabilities are at increased risk of developing dementia, particularly those with Down's syndrome. Compared with people without learning disabilities, people with learning disabilities may:

- Develop dementia at a younger age - particularly those with Down's syndrome in their late 40s or early 50s.
- Have different symptoms in the early stages of dementia.
- The incidence of myoclonic epilepsy (brief, shock-like jerks of a muscle or a group of muscles) in adults with Down’s Syndrome is often not appreciated and may lead to falls associated with dementia. Myoclonic epilepsy may be the first precursor of the development of dementia in adults with Down’s syndrome in their late 40s or early 50s.
- Be less likely to receive a correct or early diagnosis of dementia.
- Experience a more rapid progression of dementia.
- Need specific support to understand the changes they are experiencing, and to access appropriate services.

Symptoms

For those with mild learning disabilities, dementia may appear and progress similarly to dementia in the general population. For those with more severe learning disabilities, however, the initial symptoms of dementia are often less typical which can make diagnosing dementia more difficult. People with dementia and learning disabilities may experience or develop:

- Changes in behaviour and personality e.g. becoming irritable or withdrawn.
- Loss of daily living abilities such as walking and continence.
- Swallowing difficulties.
- For those with Down’s syndrome, developing epilepsy (usually myoclonic) in later life can be a sign of dementia.

Assessment and diagnosis

Making a diagnosis of dementia is often difficult, particularly in people with learning disabilities. The most helpful approach may be to look for a change or deterioration in the person’s concentration, reasoning or behaviour, or their ability to manage daily living. Family, friends and carers will play an important role in helping to identify early signs. Assessments for dementia should be included as part of annual health checks (see Factsheet 23). This is particularly important for people with Down’s syndrome, who should be assessed by the time they’re 30 to provide a baseline comparison for assessment.

Assessments should be carried out by a multi-disciplinary team in a timely and thorough way in order to rule out other explanations that may be treatable (such as depression, constipation, side effects of medication or changes to sight or hearing), and to enable access to advice, information and treatment. Assessment should include: a detailed personal history including talking to carers or family to establish any changes; a full health assessment to rule out other potential causes of symptoms such as vision or hearing problems; psychological and mental state assessments to rule out explanations such as depression; and it may also be appropriate for the person to undergo special investigations such as brain scans.

Diagnosis should identify the type of dementia, as this will impact on symptoms, progression and treatment.

After diagnosis

A care plan should be developed by a multi-disciplinary team and services should be proactive rather than reactive, planning for issues that are likely to arise such as swallowing difficulties, incontinence and reduced mobility, as well as making preparations for end-of-life planning while the individual has the capacity to be involved. Dementia can affect a person’s sense of reality (e.g. mirrors may become confusing) and a calming and familiar environment can help. Family, carers and friends should work with health and social care professionals to understand and prevent triggers for confusion or agitation. Routine can be an important tool e.g. structuring days so that activities happen in the same order, as well as memory boxes or ‘life story books’ to facilitate long term memory.

Whilst there is no cure for dementia, there are some medications that can improve symptoms, and where these are of benefit they should be made available to people with learning disabilities.

Summary of key points

People with learning disabilities may be more likely to have dementia, and less likely to receive an early or correct diagnosis of dementia than people without learning disabilities. The person’s carers or family should work with professionals to understand and monitor any changes in the person’s behaviour, and to manage their symptoms.

Additional sources of information

Alzheimer’s Society

- Learning disabilities and dementia www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103
- Assessment and diagnosis www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=260
- Types of dementia www.alzheimersresearchuk.org/about-dementia/types-of-dementia/
- Progression of dementia www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=133

Improving health and lives: Learning disabilities observatory

- Making reasonable adjustments to dementia services for people with learning disabilities www.improvinghealthandlives.org.uk/uploads/news/vid_19037_RA%20Dementia1908Final%20LD%20edit%20docxPHE-2013179.pdf