

# THE **GROWTH** OF **DEMENTIA** IN LEARNING DISABILITY

People with a learning disability are living longer and developing dementia almost ten years earlier than the rest of the population. Shekhar Mukherji highlights the importance of early recognition, assessment and management of the disorder.

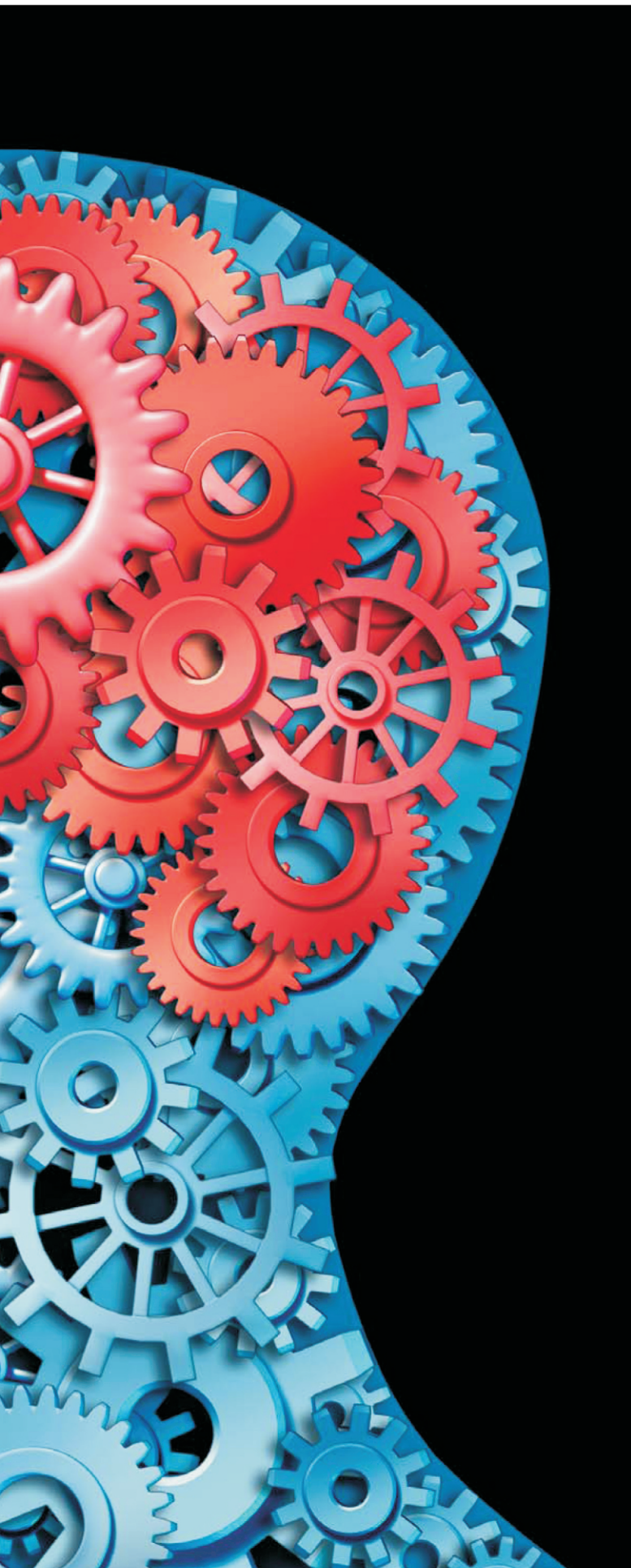
As people with a learning disability (LD) are living longer we are seeing a corresponding increase in dementia occurrence. The statistics speak for themselves. In 1900, in the United Kingdom, a person with Down's Syndrome (DS) lived on average for a heart-rending nine years. At the end of the first decade of the 21st century the figure has encouragingly risen to around 56 years. Add to this the fact that dementia in DS can present as early as 35 years. In 2010, the best estimate was of more than 7,500 people in the UK with DS and dementia; there may now be more than 1,000 people with DS developing dementia every year.

## MODELS OF CARE AND SUPPORT

There are three basic models of care and support available. The first focuses on enabling the person to 'stay in place', whether in their own home, supported accommodation or a care home. Though often considered the best option, making the necessary environmental modifications may not always be possible and there may be a negative impact on other users of the service. The second involves moving to a specialist residential service designed to support people with →







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→ this dual disability. There is a marked scarcity of such specialist services, which aim to provide a home for life in a domestic-sized environment and provide a service geared towards both disabilities. A move to a generic elderly dementia service, the last model, always provides the worst outcome for the individual but is not uncommon in today's cost-cutting environment.

### ASSESSMENT AND DIAGNOSIS

Dementia is a chronic disorder of mental functioning caused by brain disease or trauma. While it classically presents with the triad of loss of memory, skills and mood changes, in people with severe and profound LD it often presents with behavioural and health-related changes. The first step to establishing the presence of dementia is to ascertain baseline cognitive and health functioning. Frequently, people with LD will not have had such prior recorded assessments on file. It is recommended that, from age 30 years, people with DS undergo formal assessments to establish baseline cognitive and health profiles, subsequently repeated at regular intervals. For people with generic LD this should occur from age 50 years onwards. In the absence of baseline information, it is imperative to gather information about the person's normal functioning from carers, relatives and friends. Earlier recorded life story work is particularly helpful in this regard.

Dementia diagnosis requires the presence of cognitive decline over six months often with associated health-related or emotional decline, loss of language and self-care skills and uncharacteristic behaviour. Personality changes may precede memory loss when dementia develops in DS.

Generic assessment tools used to diagnose dementia are inappropriate for use in people with LD. However, many assessment tools have been developed specifically for this group. These include dementia and depression screening tools, informal questionnaires, neuropsychological assessments and assessments of daily living activities. No single battery of tests to diagnose dementia in people with LD is universally used in the United Kingdom. However, assessment should include a direct evaluation of the person and the application of a questionnaire to a close carer, relative or friend. With profound →





and multiple learning disabilities, cognitive function is so poor that changes are undetectable on testing; carer reports take precedence here.

Inexperienced or untrained assessors will not accurately record results of testing. Diagnosis may be delayed because carers have not noticed relevant behavioural changes or have increased prompting to overcome these changes. There may be an element of denial or reluctance to seek help. Concurrent medical problems often serve to confuse the picture and divert from the true diagnosis.

## PHYSICAL ENVIRONMENT

Ideally, design should be geared to cope with the complexities of the relationship between the physical environment and the care and support that takes place within it.

The environment should resemble normal housing and be calm and predictable. Colour is used to promote a calming effect and for contrast. Environmental labelling, through signage and colour, gives clues to support independent movement around the home. Glare is avoided, as are sudden changes in light levels between and within rooms. Non-reflective surfaces and noise reduction technologies are used. The

person should be able to look upon the outside world, including activities on the street. In contrast to generic dementia facilities, the furniture and fittings may need to have a modern feel to reflect the fact that people with LD and dementia tend to be younger. Surfaces should be smooth and pattern free. There should be small sitting areas promoting personalised contact in keeping with the domestic nature of the environment. Open plan kitchens allow engagement in food preparation and stimulation by the aromatic and visual contexts of food and cooking. Safe and level outside spaces are required for sitting out, walking and wheelchair transit through the entire ground level. Walking paths should be without clutter and safety features unobtrusive. Plants and shrubs should be specially selected to stimulate the senses.

## CARE AND SUPPORT

The focus shifts from enablement to preservation of existing skills. Support staff need training and experience in supporting people with this dual diagnosis. The following are a few of the crucial areas to be aware of:

### Communication

Communication styles have

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a major impact on the quality of life of those being supported and support staff need to reflect on what they are expressing through words and non-verbal cues. A good knowledge of the life history of the person with LD is essential to establish age-appropriate, person-centred communication. Tools for effective communication include passports, personal memory albums, picture mats etc; occupational, artistic and sensory stimulation are also used to facilitate self expression. Recreational activities open up new avenues for communication while reality orientation and validation therapy facilitate communication. Effective communication in dementia can be challenging as the communication skills of the person diminish.

## Health and personal care

Regular health checks, emphasising conditions commonly seen in DS and LD, and a health action plan are necessary. Medical treatment should follow National Institute for Health and Clinical Excellence (NICE) guidelines and a clearly established diagnosis and not focus on behaviour.

A balanced and nutritious diet, weight monitoring and food/fluid intake monitoring at the end of life are recommended. Personal and continence care should be delivered by trained staff with supported choice and empowerment up to the level of the person's capability.

The early recognition, assessment and management of pain are important. Support staff need training in long-term painful medical conditions, pain assessment tools and behavioural changes which may reflect pain. The life history may reveal characteristic ways the person with LD has previously responded to pain. Pain management should include non-pharmacological techniques and medical management should follow NICE/World Health Organization (WHO) analgesia guidelines and include specialist palliative services where necessary.

## UNDERSTANDING AND MANAGING BEHAVIOUR

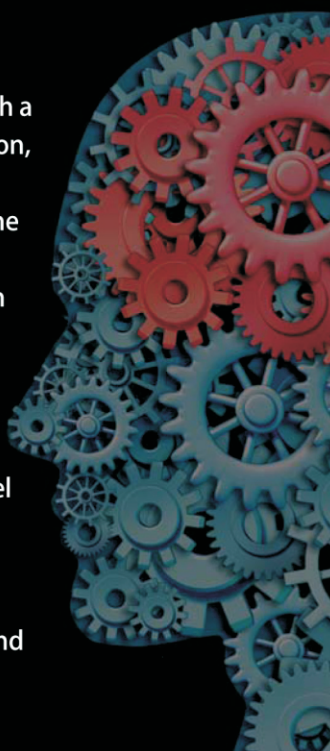
Staff and families should view the world through the eyes of the person with dementia and understand their current reality. Any intervention therefore must address the person, the environment and their interaction. Behaviour is seen as an attempt to communicate whilst making sense of an increasingly bewildering environment. The life story of the person with LD and dementia is important as the new or changed behaviour may be a return to behaviour or traits pre-dating dementia. Behavioural changes may be caused by a return to long term memories associated with the behaviour. Lastly, changed behaviour may be transitory to the stage of the person's dementia and not need any intervention. Proper behaviour analysis, including the use of mapping tools, allows for good management. Sometimes simple environmental alterations are the only interventions required. Other interventions include new communication strategies, positive behaviour programming, counselling, medical evaluation and treatment.

In conclusion, it is now vital that all concerned agencies work together to provide good outcomes for this vulnerable user group.

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## REAL LIFE EXAMPLE

A 49 year old man with DS presents with a six month history of increasing confusion, insomnia, urinary incontinence and withdrawal. A formal assessment is done which is inconclusive - there is some evidence of global decline, especially in social skills. History from another carer indicates recurrent UTIs in the past and the GP is involved, a UTI is diagnosed and treated. Cognitive abilities and social skills return to an acceptable level but not to the previous level. A review at six months does not reveal further decline but at 18 months there is clear evidence of further cognitive decline and a diagnosis of dementia is made.



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