

## Deaf with dementia – from misdiagnosis and isolation to a future of good practice

### The challenge of dementia – inclusion of everyone

With hundreds of thousands of people in the UK affected, and numbers projected to double in the next 30 years, dementia is likely to touch all our lives in some way. The challenges are tremendous.

The UK government's March 2012 pledge to double funding for dementia is important news, but it is vital everyone affected by this isolating health condition is fully included.

Deaf people in the British Sign Language (BSL) community have had a long struggle to access dementia diagnosis and support, with serious implications for quality of life and treatment. Now, for the first time, a cognitive test for dementia has been developed for BSL users. This is an important step towards the radical improvements needed to ensure timely medication and appropriate care for Deaf people living with dementia.

A spotlight on the Deaf community highlights the particular challenges inherent in dementia provision for other minority language and culture groups. Discussion around sign language users with dementia also extends to the impact of deafness in dementia in general. One in seven of us will become deaf or hard of hearing, and this – as with dementia – is associated with increasing age. Anything that further hinders communication where there is cognitive decline has serious implications – for diagnosis, management and the personal experiences of individuals and their families. More research is needed on the high correlation between sensory impairments and dementia.

### The Deaf community, health and dementia

About 70,000 people in the UK are profoundly deaf, either from birth or before acquiring spoken language. These people make up the Deaf ("D/deaf" denotes culturally Deaf/being deaf) community, which has its own language, culture and history. British Sign Language (BSL) is their first or preferred language. BSL is not a series of gestures or a visual way to represent English, but an independent language. Talk in BSL occurs "without spoken words in which meaning is generated through the grammatically precise use of movement, handshape and facial expression within space" (Sutton-Spence & Woll, 1999).

Members of the Deaf community experience barriers in accessing healthcare. Communication difficulties in medical settings stem from a lack of awareness of Deaf language and culture. Limited healthcare information is available in BSL and there is often inadequate provision of interpreting services. Appropriate assessment and care tailored to meet the needs of Deaf people with dementia and those with other neurological conditions is almost non-existent in the UK.

For dementia, improvements in three key areas are vital for equal access to healthcare:

#### 1. Early diagnosis of dementia is essential

Dementia in Deaf people is currently diagnosed late - when difficulties become obvious - or not at all. It may be misdiagnosed or missed in Deaf people because professionals are unable to communicate with them. Until very recently there has been no appropriate cognitive test for sign language users. Tests used with hearing people do not work well with Deaf people because of the differences between English and BSL, as well as cultural and cognitive differences. BSL users'

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early development is shaped by deafness, and often, communication deprivation and delayed language. Thinking and memory are also shaped by use of a visuospatial rather than a spoken language. Deaf people may have different points of reference, for example, when asked to name famous people – something that is often used as a marker for cognitive decline. In other cases an interpreter's translation of an English test into BSL can create unrecognised disadvantages or advantages that distort the assessment of a person's abilities. Thus the assessment of Deaf BSL users poses a unique challenge.

In the Alzheimer's Society report *Dementia 2012: A national challenge*, launched in March in parallel with the government's plan to improve dementia care and research by 2015, the figures around diagnosis are stark. It is estimated that 670,000 people in England have dementia, but that 42% of those with dementia do not have a diagnosis. This represents 400,000 people who do not know they are living with the condition. For Deaf people this percentage is estimated to be much higher. Since the symptoms of dementia may not become fully apparent until many years after cognitive impairment has started, the impact in medical, emotional and financial terms is greater as positive interventions are delayed. Earlier diagnosis for *all* is imperative. It enables better medical treatment and gives time for better care to be put in place. To address this gap the government wants to set up screening programmes in GP surgeries. However these will not address the needs of BSL users.

## 2. Deaf people who use sign language must be assessed with linguistically and cognitively appropriate tests

An important first step has been made to improve early diagnosis and management of dementia among Deaf people. A BSL Cognitive Screening Test and BSL Test of Verbal Memory and Learning have been developed as part of the 2010-2012 Deaf with Dementia (DwD) project supported by the Alzheimer's Society. The project is a partnership between the University of Manchester, the Deafness Cognition and Language (DCAL) Research Centre at University College London (UCL), City University London and the Royal Association for Deaf People (RAD). DCAL and associates based at City University London are responsible for test development. As a direct result, Deaf individuals can be properly assessed for dementia and other neurodegenerative conditions. They can now be referred to

the Cognitive Disorders Clinic at the National Hospital for Neurology and Neurosurgery, London. Here the new tests are being used as part of full medical and neuropsychological assessment. This is a positive development but the service is limited and already very over-subscribed.

Work is ongoing to build understanding about cognitive decline and dementia in Deaf people. Further research is key, as is greater access to neurological and neuropsychological tests. Ideally there should be a specialist service providing neurological assessment for Deaf people across the UK. Other conditions for which cognitive manifestations in signers are as yet unknown need to be documented. The study of Deaf people gives new perspectives which increase our understanding of neurological disorders in both deaf and hearing people, and provide new insights into human cognition in general.

## 3. Services need to be radically improved for Deaf people living with dementia

Coordinated service provision for Deaf people with dementia in the UK is woefully lacking, from diagnosis to follow-up care. Services for Deaf older people are few and specialist provision for Deaf people with dementia virtually non-existent.

GPs often misread dementia symptoms in Deaf individuals; within hearing environments an older Deaf person's lack of interaction is easily attributed to communication barriers rather than cognitive decline; due to a lack of research on dementia and sign language it is unclear how a BSL user's language might change with the condition; there is little or no research on the experience of dementia from the perspective of Deaf people themselves or Deaf people's experience as dementia carers; there are no dedicated UK nursing homes for Deaf dementia patients – so Deaf individuals end up in hearing dementia care homes, where they experience severe isolation, and this may accelerate cognitive degeneration and ill health. For example, shared cultural memories, such as attending Deaf boarding schools, are important amongst Deaf people and these may be overlooked in standard therapy sessions. The *Deaf with Dementia* project is currently undertaking studies with the Deaf community around dementia that should help inform improved care. Better care is integral to the government's *National Dementia Strategy*, with which the DwD project is working closely.

