

Briefing to West Oldham District Executive

Dementia in Oldham

Portfolio Holder:

Cllr E.Moores Cabinet Member for Health & Wellbeing

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Reason for report

At a recent meeting of the Oldham West District Executive, members were asked to appoint a District Dementia Champion. Cllr Jabbar was nominated and he joins seven other members who are Dementia Champions for their respective Districts.

It was also requested that a further report that provides them with a better understanding of dementia, what the prevalence of Dementia is in Oldham and how that compares with other areas. Additionally, a focus on Dementia within BAME communities (attitudes, stigma, and interventions) was requested given the demographic of the Oldham West district.

Recommendations

The Oldham West District Executive is asked to:

- Note the content of this report,
- Discuss the information included in this report
- Commit their support to helping to make Oldham as Dementia Friendly as possible.

1. Report details

1.1 What is Dementia?

According to the Dementia Friends website, Dementia is;

“caused by a number of diseases that affect the brain. The most common is Alzheimer's but diseases also include vascular dementia, dementia with Lewy bodies and Pick's disease.

Different types of dementia affect the brain at different rates and in different ways, but other things like someone's personal circumstances, the people around them and the environment in which they live, will affect their experience of dementia. Dementia progresses in a way that is unique to each individual.

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour.

It is true that more people over 65 have dementia but it is not exclusively an older person's disease; younger people get dementia too.”

One of the key things to know is that each person is unique and will experience dementia in their own way. The different types of dementia also tend to affect people differently, especially in the early stages. Other factors that will affect how well someone can live with dementia include how other people respond to them and the environment around them.

A person with dementia will have cognitive symptoms (to do with thinking or memory). They will often have problems with some of the following:

- day-to-day memory – for example, difficulty recalling events that happened recently
- concentrating, planning or organising – for example, difficulties making decisions, solving problems or carrying out a sequence of tasks (such as cooking a meal)
- language – for example, difficulties following a conversation or finding the right word for something
- visuospatial skills – for example, problems judging distances (such as on stairs) and seeing objects in three dimensions
- orientation – for example, losing track of the day or date, or becoming confused about where they are.

A person with dementia will also often have changes in their mood. For example, they may become frustrated or irritable, apathetic or withdrawn, anxious, easily upset or unusually sad. With some types of dementia, the person may see things that are not really there (visual hallucinations) or strongly believe things that are not true (delusions).

Dementia is also a progressive illness, which means the symptoms gradually get worse over time. How quickly this happens varies greatly from person to person. As dementia progresses, the person may develop behaviours that seem unusual or out of character. These behaviours may include asking the same question over and over, pacing, restlessness or agitation. They can be distressing or challenging for the person and those close to them.

A person with dementia, especially in the later stages, may have physical symptoms such as muscle weakness or weight loss. Changes in sleep pattern and appetite are also common.

1.1.2 Young on-set Dementia

People with dementia whose symptoms started before they were 65 are often described as 'younger people with dementia' or as having young-onset dementia. The age of 65 is used because it is the age at which people traditionally retired. However, this is an artificial cut-off point as opposed to having any biological significance.

Early-onset dementia is caused by broadly similar diseases to dementia in older people ('late-onset dementia'), but there are some important differences. There is a wider range of diseases that cause young-onset dementia and a younger person is much more likely to have a rarer form of dementia.

Young-onset dementia is also more likely to cause problems with movement, walking, co-ordination or balance. This is one reason why younger people with dementia may see a neurologist (a specialist in diseases of the brain and nervous system) rather than - or as well as - a psychiatrist (a specialist in mental health).

However, people under 65 do not generally have the co-existing long-term medical conditions of older people - especially diseases of the heart and circulation. They are usually physically fitter and dementia may be the only serious condition that a younger person is living with.

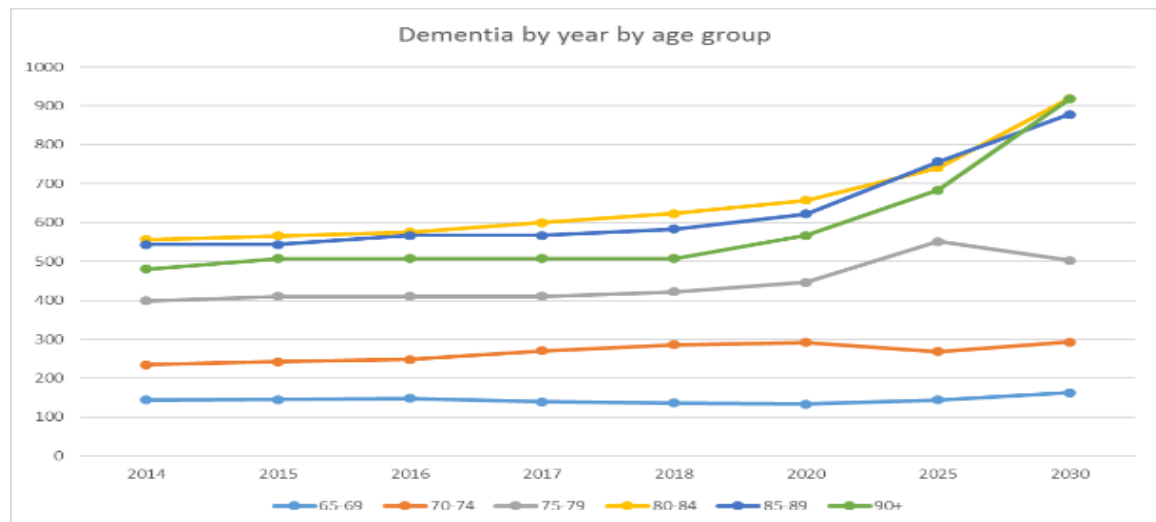
Early-onset dementia is more likely than late-onset dementia to be hereditary. In perhaps 10% of all people with young-onset dementia the condition seem to have been inherited from a parent. If dementia has been inherited, the diagnosis may have implications for birth relatives of the person such as their siblings (brothers and sisters) or children.

1.2 Dementia Prevalence in Oldham – what we know

Estimated Dementia Diagnosis Rate (+65)	= 83.4% (3 rd highest in North West)
England	= 67.9%
North West	= 73.2%
Dementia Prevalence (+65)	= 4.91%
England	= 4.29%
North West	= 4.46%

We know that we have an ageing population and the prevalence of dementia is increasing. The Department of Health statistics state that 1 in 3 people over the age of 65 will live with some form of dementia before they die. The diagram below

shows at a local level the estimated projection (up to the year 2030) of dementia prevalence in the borough broken down by the year and age range.



1.3 Services in Oldham for Dementia

The Council and CCG have worked together over the past few years to ensure they coordinate the commissioning of Dementia support services in the borough.

These services are;

1.3.1 Dementia Action Alliance Support – Making Space - includes developing and support the Oldham Dementia Action Alliance, promoting dementia awareness week, organising the Oldham Dementia conference and developing the dementia friends programme.

1.3.2 Memory Assessment Service – Pennine Care Foundation Trust - offers a diagnostic and treatment service for dementia as well as wide range of post diagnostic support for people found to have dementia, their families and carers. The aim of the service is to promote early diagnosis of dementia and provide on-going emotional and practical support in order for people to live well with dementia.

The service offers:

- A memory liaison practitioner – a specially trained link nurse who can offer information and advice about dementia as well as completing annual dementia reviews.
- Post diagnostic support and information groups.
- Occupational therapy, psychology assessments and support and speech and language therapy.
- Advice and support to help people to remain independent and live well with Dementia.
- A drop in café for younger people living with dementia
- Dementia awareness sessions for anyone concerned with memory problems held weekly in libraries around Oldham

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- 1.3.3 Mental Health Care Home Liaison Team Oldham – Pennine Care Foundation Trust - provides mental health care and treatment to care home residents across Oldham. The team also provide education and support to care home staff and in primary care.
 - 1.3.4 Making Space also provide post-diagnosis support to those who have been diagnosed with Dementia, and their families and carers, helping them deal with the diagnosis and help them to make the adaptations in their lives to ensure they are prepared and comfortable with the support around them.
 - 1.3.5 There are other community focused interventions provided by organisations such as the ‘Enhanced memory service’, which is made up of the memory assessment service, AGE UK, Alzheimers society and Making Space. Additionally, there are numerous community led initiatives across Oldham, such as the Springboard Carers group, which is a charity in its own right, and the Dementia Engagement Empowerment Programme (DEEP) group “*Let’s be Heard*” which is a group ran by/with people living with Dementia

1.4 Dementia within BAME community.

More than 25,000 older black and minority ethnic (BME) people live with dementia in the UK, in part due to vascular risk factors such as hypertension often found in African-Caribbean and South Asian UK populations.

For some people, the experience of what it means to live with dementia will be unfamiliar. They may not have seen or cared for someone with dementia in their family if they left their country of origin for work when young, for example. Knowledge of dementia and dementia services is limited in other BME groups. For example, in one Chinese community, negative perceptions of dementia resulted from poorly-translated terms which give dementia the meaning of ‘lost intelligence disease’. A similar challenge is seen within South-East Asian communities, where there is no word for ‘Dementia’. Instead, the disease is seen more as madness, rather than the A perceived or actual cultural bias in assessment tests and diagnosis may limit their value or appropriateness for some BME older people (3).

Engagement with social and health care services may be resisted by some BME communities because they fear discrimination or they find services are difficult to access. Chinese older people said they feared a relative in care would be the only person from that community and thus be isolated. A delay in seeking support may mean the person is not in contact with services until disease is advanced or the person or family is in crisis.

There is evidence that minority ethnic carers are more likely to be isolated from mainstream services. Some may view using a service as a source of shame. In Islam, Hinduism and Sikhism the duty of care is apparent or is regarded as a ‘test from God’. There is stigma around dementia in some cultures; it may be regarded as a punishment for past misdemeanors or a family member with dementia may damage the marriage prospects of a young relative.

There is also evidence that people from BME communities are not sure where or how to find information about dementia. This is exacerbated by language barriers or when people have lost cognitive skills, or if online information is not available in community languages. People may confuse the symptoms of dementia with ‘normal ageing’ and not seek the support that is available. That is why access to sector organisations which can support navigation of the system is so important.

Establishing links between the commissioners and service providers with culturally-appropriate voluntary and community groups as well as interpreters who can support communication with families will provide the opportunity to discuss diagnosis and treatment options. There are examples of good practice in dementia care for those from BME communities but expertise needs to be shared more widely across the provider sectors.

In Oldham, work has been done to try and increase and improve the awareness of Dementia and the Dementia support services that are available in the borough. Work has included:

- Amending the ‘Dementia Friends’ training programme to ensure it is more relevant and practical for BME communities.
- ODEM (Oldham Ethnic Minority Reference Group) – group designed to build relationships, improve awareness and provide co-designed and culturally appropriate information, training and post-diagnostic support to Oldham’s ethnic minority groups.
- Axa Homes Ladies Group
- European Islamic Centre group

Whilst anyone is welcome at any of the groups running for those dealing with Dementia, Making Space have indicated that it is very rare that anyone from the BAME community would access them, instead preferring a service within their own community that is specifically tailored for and targeted at them. It can also be hard mixing men with ladies and vice versa. So although Oldham does have a fantastic offer of overall support for those with Dementia, Making Space and the other providers have had to work hard in developing something specific for south Asian communities.

2. Recommendations

2.1 The Oldham West District Executive is asked to:

- Note the content of this report,
- Discuss the information included in this report
- Commit their support to helping to make Oldham as Dementia Friendly as possible.