Harrow
JSNA Online

# PUBLIC HEALTH BRIEFING ON DEMENTIA

## KEY MESSAGES

- It is estimated that 2.524 people are living with dementia in Harrow. Furthermore, it is estimated that over 935 people with dementia in Harrow have not yet been diagnosed or whose condition in not known to their GP.
- The percentage of people diagnosed with Dementia in relation to the prevalence of dementia in Harrow at August 2018 is 64%
- There is a considerable economic cost associated with the disease estimated at £23 billion a year which is predicted to triple by 2040.
- Harrow has one of the highest proportions of older residents ages 65 and over compared to other London boroughs at 15.7%
- Harrow is ranked 7$^{th}$ in London for the proportion of residents aged 65 and over
- Harrow has seen an increase in the number of older residents since 2011. The population of those aged 65 and over was 14.1% and this increased to 15.7% in 2018
- Stanmore Park has the highest proportion of people over the age of 65 with 23.5%, whilst Roxbourne, Greenhill, Marlborough and Wealdstone have fewer than 12% of older residents over 65.
- The prevalence of dementia in Females over the age of 65 in Harrow is estimated as 8.2% compared to 6.1% for males.
- Harrow CCG, Harrow Local Authority and Public Health Harrow are committed to improving the patients journey in terms of living well with dementia.
- Harrow has to look at ways of developing effective preventative/management intervention that could offset some of these significant costs in view of its local fiscal challenges.
- In Harrow, there has been an increasing focus on the Dementia Diagnosis rate, to enable easy access to care, support and advice following diagnosis. The intention is to increase the level of diagnosis to ensure appropriate post diagnostic support for patients and carers creating a more Dementia friendly borough

## BACKGROUND

Dementia is a growing challenge. As the population ages and people live for longer, it has become one of the most important health and care issues facing current times. Dementia mainly affects older people (age 65 and above) and it may also run in families. However, for some dementia can develop earlier presenting different issues for the person affected, their carer and their family.

Dementia can be described as a brain disease which often starts with memory problems, but goes on to affect many other parts of the brain, producing: memory loss, feeling anxious, language impairment, disorientation, hallucinations, change in personality, self-neglect and behaviour which is out of character.

Studies have shown that dementia is progressive, meaning that is gradually gets worse. And sadly, there is no cure for most forms of dementia, although if detected early there are ways to slow it down and maintain mental function. As dementia affects a person's mental ability, they may find planning and organizing difficult. Eventually maintaining their independence may also become a problem. Therefore individuals with dementia usually require help from friends, relatives and carers to aid in daily activities such as feeding, dressing, washing and decision making.

It is important to get a diagnosis as it helps people to plan ahead while they are still able to make important decisions on their care, support needs and financial and legal matters. It also helps them and their families to receive practical information, advice and guidance as they face new challenges. Although Harrow has a diverse population, diagnosing people with dementia has proven to be a challenge. Generally the public have concerns over the impact on their daily lives, particularly in their jobs, social lives, cultural beliefs and in many cases the stigma associated with dementia. For these reasons, some families, carers and sufferer prefer not to seek a diagnosis when early signs of dementia are present.

Early-onset dementia is used to describe the situation where dementia is developed before the age of 65. Late-onset dementia refers to patients who develop dementia after the age of 65 although it is far more common than early-onset dementia, because dementia is primarily a disease associated with aging.

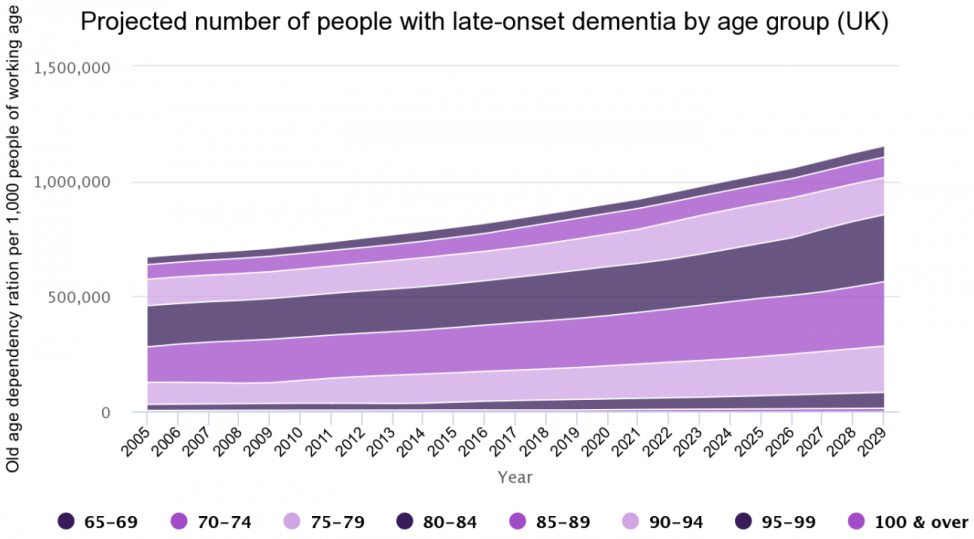
The most common causes of dementia are age-related neurodegenerative processes. These refer to diseases or injures which affect the function of the brain. There are a number of such diseases which cause dementia. The most common cause of dementia is Alzheimer's disease, followed by vascular dementia, Dementia with Lewy bodies (symptoms similar to those of Parkinson's disease), Frontal temporal dementia and Mild cognitive impairment. It is important to make a distinction between the different underlying causes of dementia because they vary in the range of symptoms suffered and the rate of progression of symptoms.

## NATIONAL CONTEXT

It is estimated that about 850,000 people are living with dementia in the UK. It is difficult to know the exact number of people living with dementia due to it gradual nature, the mild early-stage symptom and low diagnosis rate. About 2 in 100 people aged 65-69 have dementia, and this figure rises to 1 in 5 for those aged 85-89 *(Dementia UK).*

Research suggests that approximately 1 in 4 patients in acute hospitals have dementia and that these needs are not currently well responded to *(Lakey 2009)*. Staff in acute settings and care homes may need extra training in caring for people with dementia and delirium.

**Fig 1: Projected UK dementia trends**




Source: Knapp M, Prince M **(2007)**. Report. Dementia UK *London School of Economics, King's College London and The Alzheimer's Society*

### The National Dementia Strategy

Dementia has become a key priority for both NHS England and the Government *(Lewis et al, 2014).* NHS England plan to achieve the following by 2020:

- Equal access to diagnosis for everyone
- GP's playing a lead role in ensuring coordination and continuity of care for people with dementia
- Every person diagnosed with dementia having meaningful care following their diagnosis
- All NHS staff having received training on dementia appropriate to their role

### The Prime Minster's challenge on dementia 2020

The goal of the new challenge is to consolidate and build on the progress made since the first challenge issued by the Prime Minister in 2012. The challenge aims to make England the best place to live well with dementia for patients and families by 2020 and the best place in the world to undertake research into dementia and other neurodegenerative diseases. The implementation plan focuses of 4 core themes: 1) Risk Reduction, 2) Health and Care, 3) Awareness and Social action and 4) Research.

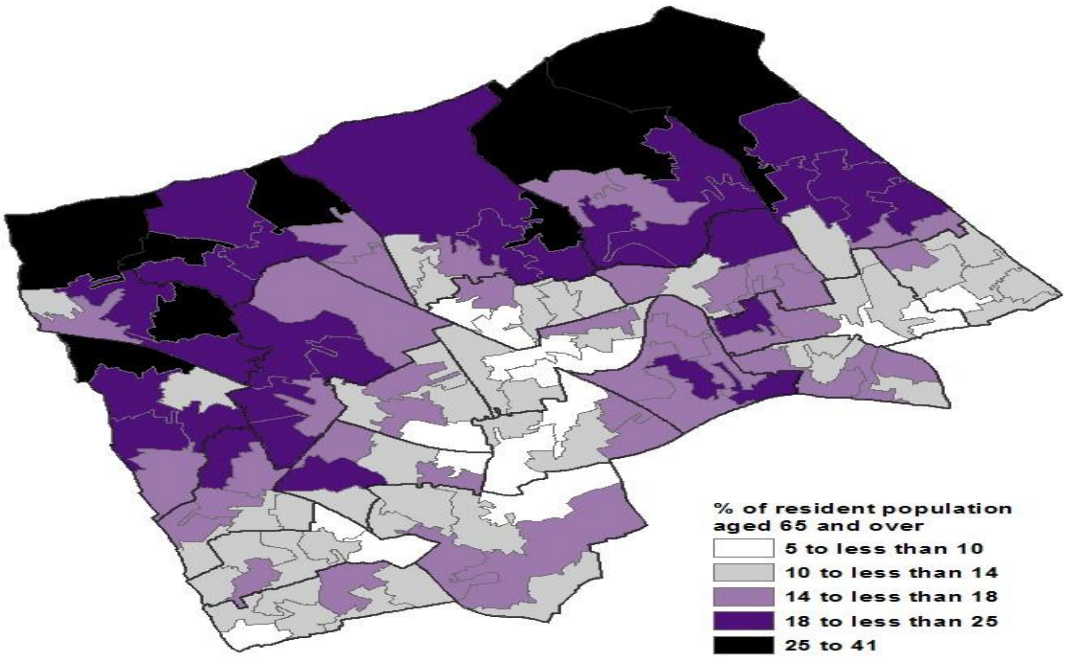
The challenge has identified 18 fundamental commitments. These commitments are specifically about improving public awareness and understanding the factors that increase the risk of

developing dementia and how individuals can reduce their risk through healthy lifestyles. This plan will involve a healthy aging campaign and access to tools such as personalised risk assessment calculators as part of the NHS Health Check.

There is emphasis on risk reduction. This will be delivered as a pilot scheme in partnership with voluntary sector organisations using the existing NHS Check to provide training around the risks of developing dementia and the steps they could take to reduce those risks. Industry sectors are encouraged to develop Dementia Friendly Charters and work with business leaders to make individual commitments and also become dementia friendly.

## LOCAL CONTEXT

**Fig 2: Residents Aged 65+** *Source: ONS LSOA Mid-Year Estimates (2016)*




Harrow has one of the highest proportions of older residents aged 65 and over compared to other London boroughs at 15.2% (this is below the national average of 16.3%). Harrow is ranked 7th in London for the proportion of residents aged 65 and over. Old age is the most important risk factor for dementia and Harrow has the highest percentage of elderly residents of the 8 boroughs in North West London for the proportion of residents aged 65 and over. (ONS LSOA Mid-Year Estimates 2016).

### Harrow's elderly population is projected to rise over the next 15 years

The population of over 65s is projected to increase to 45,500. Rises will be seen in all age groups over the age of 65 between 2018 and 2025. This increase in population will impact the number of people with dementia.

### The prevalence of late-onset dementia is greater in females than in *males*

The prevalence of late-onset dementia in females over the age of 65 in Harrow is estimated as 8.2% compared to 6.1% for males (1458 females compared to 829 males). The higher prevalence rate in females can largely be explained by the fact that women have a longer life

expectancy and so are more likely to live into their 80s and 90s, when dementia is most prevalent. (Alzheimer's Research UK / Dementia Statistic Hub **July 2018**)

## Prevalence of early-onset dementia

In early-onset dementia, symptoms start below the age of 65. Dementias that affect younger people is said to be rare and difficult to recognize. People are likely to be very reluctant to accept there is anything wrong when they are otherwise fit and well and they may refuse to be diagnosed as a consequence. It is estimated that there are 42,325 people in the UK who have been diagnosed with early-onset dementia.

Prevalence rates for early-onset dementia in BME groups are higher than for the population as a whole. This is because they are less likely to receive a diagnosis or support, due to some cultural belief, the stigma associated with dementia and inadequate knowledge about dementia care. This poses a big problem with diagnosis and a big challenge in Harrow.

Studies have shown that people with learning disability are at greater risk of developing dementia at a younger age, with 1 in 10 people with learning disability developing early-onset Alzheimer's disease between the ages of 50 to 65. 1 in 10 ages 40-49 and 1 in 3 people with Down's syndrome will have Alzheimer's in their 50s (Source -Dementia UK, 2nd edition **2014**, Alzheimer's; Young Dementia UK).

## Dementia and Ethnicity in Harrow

Harrow has one of the most diverse populations nationally, ranking 8$^{th}$ nationally for linguistic diversity in the Greater London Authority. The largest BAME group is of Indian ethnicity, with the borough having the largest concentration of Sri Lankan Tamils in the UK as well as having the highest density of Gujarati Hindus in the UK.

Life expectancy within the borough at 81.2 for men and 84.6 for women is better than that of England as a whole. The population of those ages 65 and over is 37,701 equaling 15.2% of the total population.

## Statutory Dementia Service in Harrow

Harrow council has a statutory duty to carry out community care assessments which will asses the person's needs and identify which services could be arranged to help meet these needs. The Council can also provide a carer's needs assessment which can help carers to access services to support them with their caring role.

## Harrow Memory Services

The Memory Assessment Service (MAS) as part of Central and North West London NHS Foundation Trust (CNWL) provide a comprehensive assessment of an individual's memory, ensuring that if dementia is an issue a diagnosis and services is available to help an individual come to terms with their diagnosis. They provide useful strategies and treatments to help people minimise their memory difficulties. Their primary objective is to help people live independently and safely.

## The Harrow Older People Community Mental Health Team

The team has 3 key functions:

- To give advice on the management of mental health problems by other professionals – in particular providing advice to primary care, such as GP surgeries, and making sure appropriate referrals are made.

- Providing treatment and care for those with short-term mental health issues who can benefit from specialist interventions.
- Providing treatment and care for those with more complex needs.

## RISK FACTORS OF DEMENTIA

Risk factors in this context translates to anything that can increase a person's risk of developing dementia. Some of these factors can be avoided or managed (modifiable risk factors) but some are impossible to control (non-modifiable risk factors).

## NON-MODIFIABLE RISK FACTORS

### Age

Increasing age is the most important risk factor for dementia. The population (35+ years) of Harrow is expected to increase by about 13,000 in 10 years from 2019-2029, with just under 60% of the growth occurring in the first five years. Overall the total number of people expected to have dementia is set to rise from 2900 in 2019 to 3700 by 2029.

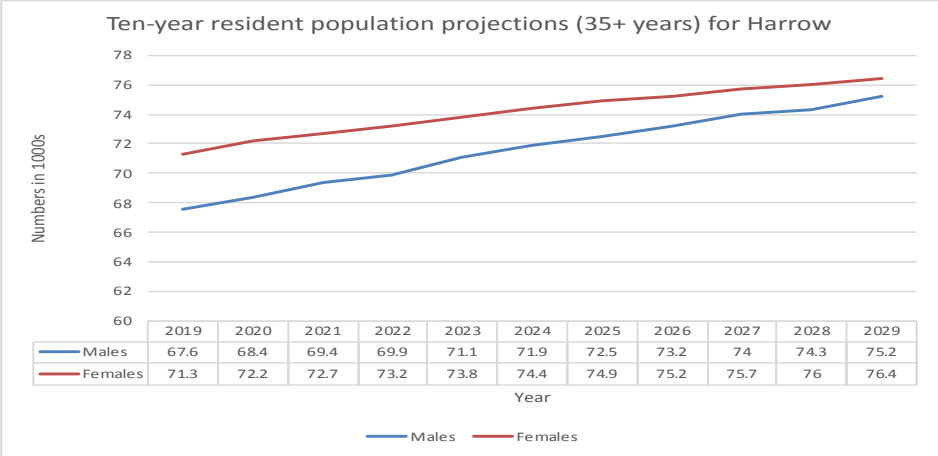



**Fig 3: Population projections**

Source: ONS 2016 based population projections 2018

### Gender

Early onset dementia is more prevalent in men compared with women, whilst late onset is marginally more prevalent in women. The distribution of subtypes is different in men and women. Alzheimer's disease is more common in women (67% in women compared with 55% in men), while vascular dementia and mixed dementias account for 31% of all cases in men and just 25% in women.

Using the gender based figures for Harrow, it can be estimated that 46% of all dementia in 2029 will be vascular dementia. Therefore, prevention through life-style factors will be important to reduce the burden of dementia in Harrow.

### Ethnicity

There is no published estimate of dementia by ethnicity in UK. About 6.1% of all people with dementia among BME groups are early onset, compared with 2.2% for the UK population as a whole. One of the reasons may be that vascular disease and risk is higher. Harrow has a higher South Asian population which is expected to grow. Public Health Programmes such as NHS health checks are a good medium to increase awareness of dementia and reduce risk. This also has implications for cultural aspects of dementia both in terms of awareness and care.

### Genetic Factors

Mutations in 3 individual's genes cause familial Alzheimer's disease. Down's syndrome is associated with an increased risk of Alzheimer's (this is rare).

### Family History

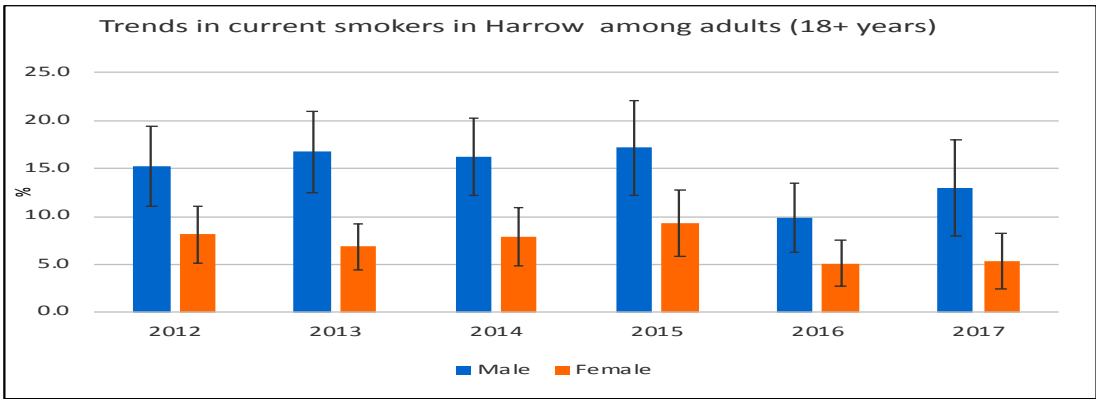
Family history of a first degree relative with Alzheimer's disease may increase the risk of Alzheimer's, however caution should be used when interpreting this information and association can only determine on an individual basis given the number of other associated variables.

## MODIFIABLE RISK FACTORS

### Smoking

Smokers have a 45% higher risk of developing dementia than non-smokers. Evidence reviewed by WHO reveals a strong link between smoking and the risk of dementia and Alzheimer's disease, and the more a person smokes, the higher the risk. It is estimated that 14% of Alzheimer's disease cases worldwide are potentially attributable to smoking. Figure 4 shows the smoking trends in Harrow has not statistically changed. Smoking prevalence is lowest in the managerial and professional occupations.

**Figure 4: Estimate of current smokers in Harrow, 2012-2017**

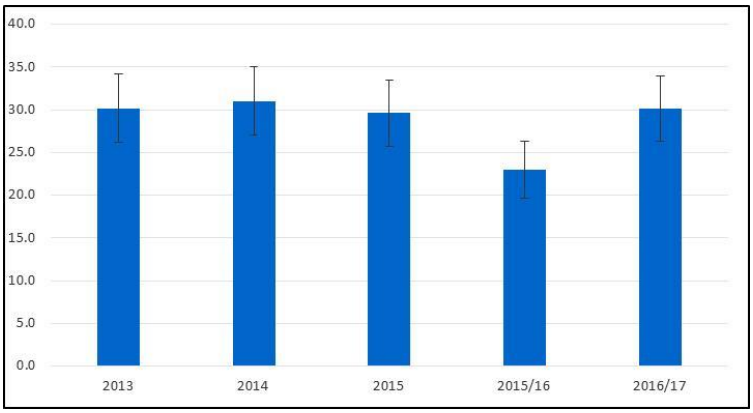



Source: WHO Tobacco knowledge summaries , June 2014 accessed at https://apps.who.int/iris/bitstream/handle/10665/128041/WHO_NMH_PND_CIC_TKS_14.1_eng.pdf;jsessionid=B11CB0747E7FB93477C606869F24527D?sequence=1

### Physical Activity

Studies have shown an association between higher levels of physical activity and a reduced risk of cognitive decline and dementia. Engaging in regular physical activity has long term benefits such as reducing the risk of dementia and dementia progression. Figure 5 shows that around 30% of the population is physically inactive over the last 5 years.

**Figure 5: Physically inactive population in Harrow % 16 + years**




## Clinical Conditions

Clinical conditions such as Hypertension, High Cholesterol, CHD, Depression and Diabetes are associated with an increased risk of both vascular dementia and Alzheimer's disease.

## Excessive Alcohol Consumption

Excessive alcohol intake is associated with Korsakoff's syndrome, and other types of dementia.

## Education Level

Additional years of education appear to offer some protection against Alzheimer's disease.

# STRATEGIC IMPROVEMENTS AND INTERVENTIONS

## Integrated care

The NHS Five Year Forward View (2014) called for new care models to achieve better integration of care across GP, community health, mental health and hospitals services as well as more joined up working with home care, care homes and the voluntary sector.

These new models will be delivered in Harrow through the development of Integrated Care where health and care partners work together to develop models of care that meet the needs of their population. This includes tackling wider determinants of health and illness e.g housing, environment, education etc.

Since August 2017, Harrow Clinical Commissioning Group, the Local Authority and Key Providers in Harrow have been working in partnership to develop and deliver integrated care initially for a subset of older adults, one group being the 65+ with dementia. The aim is to enable truly person-centred care that supports adults with significant needs to achieve the best possible quality of life with an increased focus on prevention, proactive care and self-reliance.

The programme aims to ensure that people have a personalised and co-ordinated approach for the care they need, making it easier and simpler to access support. It is intended that from 1st April 2019, Harrow CCG will commission a new model of care and services for this group of over 65s from a provider partnership. This intention is that this new model of care will be designed during September and October 2019, with testing from November 2018.

## Care Home Projects

North West London collaborative older peoples team are leading on the implementation on a series of schemes across all boroughs in North West London, with individual CCG Care Home leads taking forward the implementation of the projects locally, these projects include;

1. **Red Bag Scheme** is currently available in 13 Harrow older peoples care homes. The aim of the red bag is to streamline information sharing when a patient is transferred into A&E or via a frailty pathway. The vision is for all older peoples care homes to implement the red bag scheme within the next 6 months.
2. **Telemedicine via 111 *6.** In November 2017 111/*6 was soft launched across NW London, whereby care home staff could speak to a clinician via the 111 service. The service is about to be re launched ahead of winter 18/19 to ensure all care homes are aware of the service to reduce inappropriate LAS call outs and conveyances. Older peoples nurse practitioners are now available 8am-8pm 7 days per week to take the calls, with a view to extend the opening times to 2 am over the next few months.
3. **Recognising and acting on deterioration Training.** This is a 5 day training programme which is being delivered by St Luke's Hospice to a number of Harrow older people care homes. The training is bespoke to each care home and aims to improve the outcomes in care homes in recognising deterioration and end of life.
4. **Medicines Optimisation in Care Homes** Harrow CCG are one of four CCG's in NW London who expressed an interest in implementing the 2 year pilot. Whereby pharmacists will support care homes with medicines managements and complete medication reviews working closely with the relevant GP's. Harrow CCG are working in partnership with LNWHT, who will recruit and manage the pharmacists. The pilot is due to commence by January 2019 and will run initially for 2 years
5. **Leadership training programme – My Home Life.** All care home managers were invited to apply to take part in the training programme. For Harrow there are 13 care homes that are part of the training programme which is provided by City University. The training is due to end in March 2019

## Delivering the 2020 Roadmap (Prime Minister's Challenge on Dementia)

Key points of the action plan are taken as commitments for local focus in Harrow. The full list of actions at a national level can be seen on-line at:

https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime- ministers-challenge-on-dementia-2020

## Where are we now

Significant progress has been noted since the 2010 to 2015 strategy, with only a few mentioned below:

- Partnerships working between the Memory Assessment Service (MAS), GP's, Acute Hospitals, and through referral agencies
- Weekly Local Authority engagement with older people services, CCG and Acute Mental Health services to prevent delayed transfers of care.
- Post diagnostic information packs given to all service users and carers which include information on Housing benefits, community transport and various voluntary and community sector organisations

## Where we want to be

A lot of work is being done to address the stigma and cultural taboo associated with dementia where many families are reluctant to seek help and miss out on health & social care interventions. These include; medication, carer, support, advice, family friendly housing, dementia friendly transport, financial help for both carers and users through dementia disability living allowance and carers allowance.