Harrow CCG and Harrow Council

Joint Dementia Strategy

2018 – 2021

Draft Version: Final

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EXECUTIVE SUMMARY

Dementia is the term used to describe a progressive illness that usually harbours a number of symptoms including memory loss leading to a decline in a person's functioning. The condition does not only affect the memory but also affects intellect, rationality, social and emotional reactions.

We recognise that living with dementia and supporting a person with dementia can be very challenging and that situations can arise that are difficult for the person with dementia or those supporting them. We believe that working collaboratively we can deliver sustained improvements in dementia services and make Harrow more dementia friendly.

The condition is sometimes associated with stigma and cultural taboo which often leads to social exclusion, discrimination and disempowerment in some cases. The stigma affects a person's ability to seek help which, in turn, affects the process of early diagnosis and assessment as well as referral to services and support.

The Royal College of Psychiatrist describe Alzheimer's disease as the most common cause of dementia which accounts for about 7 in 10 of all dementias. It typically begins with memory problems and slowly gets worse over time. People will often notice that they can't remember things that happened recently, even though they can still remember what happened years ago. They will often find that they have difficulty recalling particular words and naming objects.

Vascular dementia is another form of dementia which is caused by the blood vessels supplying the brain becoming damaged or blocked. This can lead to small strokes, or parts of the brain dying, as they are starved of oxygen and nutrients. This dementia can come on more quickly than Alzheimer's. Someone with vascular dementia is more likely to suffer from conditions which lead to blocked arteries, such as high blood pressure, smoking, diabetes or high cholesterol.

We are working hard to raise community awareness about the effects of the stigma associated with dementia, to address the need to change the way people approach dementia, make recommendations for further action and to empower people living with dementia to achieve their potential.

Harrow CCG, Harrow Local Authority and Public Health Harrow are committed to improving the patient's journeys in terms of living well with dementia. 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.

The percentage of people diagnosed with Dementia in relation to the prevalence of dementia in Harrow at August 2018 is 64%. Both the prevalence rate and the number of people being diagnosed have risen 14% since 2015.

STATUTORY AND NON-STATUTORY GUIDANCE

On the 20 June 2018 the National Institute for Health and Clinical Excellence published 'Nice Guidelines for Dementia focusing on; assessment, management and support for people living with dementia and their carers.

The guideline complements existing legislation and guidance and aims to describes how services and professionals can provide high-quality care and support.

The Prime Minister's Challenge on Dementia 2020 sets out the UK Government's strategy for transforming dementia care within the UK. The aims of the strategy include:

- improving diagnosis, assessment and care for people living with dementia
- ensuring that all people living with dementia have equal access to diagnosis
- providing all NHS staff with training on dementia appropriate to their role
- ensuring that every person diagnosed with dementia receives meaningful care.

Since the 2006 NICE guideline on dementia was developed, key new legislation has been implemented. The Care Act 2014 created a new legislative framework for adult social care, and also gives carers a legal right to assessment and support.

<u>Relevant legislation and statutory guidance</u>

- NHS England (2015) Accessible Information Standard
- Care Act 2014
- Health and Social Care Act 2008 (Regulated Activities) Regulations 2014
- Department of Health (2014) Care Act 2014: Statutory Guidance for Implementation

- Department of Health (2014) Positive and Proactive Care: Reducing the need for restrictive
- Interventions
- Health and Social Care Act 2012
- Equality Act 2010
- Mental Capacity Act 2005
- Human Rights Act 1998

Relevant policies and non-statutory guidance

- Information Commissioner's Office (2017) Guide to the General Data Protection Regulation
- NHS England (2017) Dementia: Good Care Planning
- NHS England (2015) Implementation guide and resource pack for dementia care
- Skills for Health, Health Education England and Skills for Care (2015) Dementia Core Skills Education and Training Framework. This framework was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health and Health Education England in partnership with Skills for Care
- Department of Health (2014) NHS Outcomes Framework 2015 to 2016
- Department of Health (2014) Adult Social Care Outcomes Framework 2015 to 2016

UNDERSTANDING THE CHALLENGE

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 the world. In England it is estimated that around 650,000 people have dementia. In the whole of the UK, the number of people with dementia is estimated as 850,000.

Dementia mainly affects older people, and after the age of 65, the likelihood of developing dementia roughly doubles every five years.

However, for some dementia can develop earlier, presenting different issues for the person affected their carer and their family. There are around 540,000 carers of people with dementia in England. It is estimated that one in three people will care for a person with dementia in their lifetime. Half of them are employed and it's thought that some 66,000 people have already cut their working hours to care for a family member, whilst 50,000 people have left work altogether.

There is a considerable economic cost associated with the disease estimated at £23 billion a year, which is predicted to triple by 2040. This is more than the cost of cancer, heart disease and stroke.

What is dementia?

Dementia can be described 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 (not knowing the time or place)
- Change in personality (becoming more irritable, anxious or withdrawn; loss of skills and impaired judgment)
- Self-neglect
- Behaviour which is out of character

Studies have shown that dementia gets worst. It is more common in older people and it may also run in families. A person with dementia may lose empathy, they may see or hear things that other people do not (hallucinations), or they may make false claims or statements.

Contrary to common belief, dementia is not one specific disease but is an umbrella term that describes a wide variety of symptoms that damages the brain cells. Dementia is progressive, meaning that it gradually gets worse. And sadly, there is no cure for most forms of dementia. “People typically think Alzheimer’s is dementia. In fact, it is one of the many forms of dementia.

As dementia affects a person's mental abilities, they may find planning and organizing difficult. Maintaining their independence may also become a problem. A person with dementia will therefore usually need help from friends or relatives, including help with decision making. Patients may have difficulty feeding, dressing and washing themselves and are highly dependent on carers.

Most types of dementia can't be cured, but if detected early there are ways to slow it down and maintain mental function. Everyone's experience of dementia is unique and the progression of the condition varies. Some symptoms are more likely to occur with certain types of dementia.

Why it is important to get a diagnosis

An early diagnosis opens the door to future care and treatment. It helps people to plan ahead while they are still able to make important decisions on their care and support needs and on financial and legal matter. It also helps them and their families to receive practical information, advice and guidance as they face new challenges.

Diagnosis will help them gain access to resources and support, make the most of their abilities and also benefit from drug and non-drug treatments available.

Why people may shy away from diagnosis

Harrow has a diverse population and diagnosing people with dementia is a challenge. Generally the public have concerns over the impact on their daily lives. Particularly in their jobs, social lives, cultural belief and the ability to drive and in many cases the stigma is associated with dementia. For these reason, some families, carers and suffers prefer not to seek a diagnosis when early signs of dementia are present**.**

- 49 % of people are worried that they would be seen as mad after a diagnosis of dementia
- 56% of people put off seeking diagnosis for up to a year of more.
- 62% of people feel that their life is over after diagnosis.
- 58% of people feel that they will struggle to join in conversations or enjoy the things they used to enjoy the things they used to.
- 42% believe that once a person living with dementia stops recognising loved ones, they don't benefit from spending time with them.
- 68% believe that they will be a different person if they were diagnosed of dementia.
- 68% of people feel isolated following a diagnosis of dementia
- 85% of people want to stay at home as long as possible after a diagnosis of dementia.

Source: Alzheimer's Society / Dementia statics.org (2016)

Early and Late onset dementia

Early-onset of dementia is used to describe the situation where dementia is developed before the age of 65. It is estimated that at least 42,000 younger people are living with dementia in the UK **(2014)** Prince M et al, Dementia UK.

Late-onset of dementia refers to patients who develop dementia after the age of 65. Late-onset dementia is far more common than early-onset dementia, because dementia is primarily a disease associated with ageing. However the underlying disease for all age ranges is the same.

Underlying causes of dementia

The most common causes of dementia are age-related neurodegenerative processes. These refer to diseases or injuries 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.

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. The key features of the most common underlying causes of dementia are summarised as:

Alzheimer's disease:

- The most common cause of dementia.
- Damaged tissue builds up in the brain to form deposits called 'plaques' and 'tangles'. These cause the brain cells around them to die.
- Characterised by a gradual progression of symptoms.
- The first symptoms to appear are usually a loss of memory.
- Learning new information becomes harder
- As symptoms progress, the person will have increasing difficulty carrying out daily functions.

Vascular dementia

- This is when the arteries supplying blood to the brain become blocked
- This leads to small or big strokes
- Parts of the brain die as they are starved of oxygen.
- Unlike Alzheimer's, progression of symptoms may be sudden (after a stroke) or step-wise rather than gradual.

Dementia with Lewy bodies:

- Associated with protein deposits that develop inside nerve cells in the brain and affect the function of the brain
- Type of dementia may have symptoms similar to those of Parkinson's disease, such as tremors and slowness of movement.

- The disease is progressive, although a person's level of function may fluctuate on an hourly basis.

Front temporal dementia

- Is rare, and can be caused by a number of degenerative diseases affecting the brain including Pick's disease.
- In the early stages of disease, memory is often intact, but personality and behaviour change are apparent.
- Incontinence may be a relatively early feature of the disease.
- This often starts in people in their 50s and 60s.

Mild cognitive impairment

- When memory problems are more than you would expect for your age, but not bad enough to be called dementia. About 1 in 3 people with this problem may develop dementia

RISK FACTORS FOR DEMENTIA

Risk factor in this context means anything that can increase a person's risk of developing dementia. Some of these factors can be avoided or managed but some are impossible to control. For example; high blood pressure can cause strokes and strokes can cause vascular dementia, high blood pressure is a risk factor for vascular dementia.

The most important non-modifiable risk factor for dementia is age. A number of modifiable risk factors for dementia exist. These include the risk factors for vascular diseases, such as diabetes, hypertension, smoking and high cholesterol, which all increase the likelihood of both vascular dementia and Alzheimer's disease. Excessive alcohol consumption is also an important modifiable risk factor.

Risk factors for dementia

Risk factor	**Comments**
Non-modifiable risk factors	
Age	Increasing age is the most important risk factor for dementia.
Sex	Alzheimer's disease is slightly more common in women, particularly in those over 80 years of age

Genetic factors	Mutations in 3 individual 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	
Hypertension	Associated with an increased risk of both vascular dementia and Alzheimer's disease.
High cholesterol	Associated with an increased risk of both vascular dementia and Alzheimer's disease.
Diabetes	Associated with an increased risk of both vascular dementia and Alzheimer's disease.
Smoking	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 of types of dementia.
Educational level	Additional years of education appear to offer some protection against Alzheimer's disease.

Source: Kester and Scheltens. Dementia UK: The Bare Essentials Pract Neurol **(2009)**; **9:**241-251

People with learning disabilities and Dementia

People with learning disabilities, particularly those with Down's syndrome, are at increased risk of developing dementia. Professionals must ensure additional time and adjustments particularly with communication allowing expression on how they feel if their abilities have deteriorated. Communication difficulties will make it harder for others to assess change.

THE NATIONAL CONTEXT

Prevalence of dementia in the UK

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 its gradual nature, the mild early-stage symptom and low diagnosis rate.

About two in 100 people aged between 65 and 69 have dementia, and this figure rises to one in five for those aged between 85 and 89 (*Dementia UK).*

In terms of the rising care needs of people with dementia, it is estimated that in England over the next 30 years it will more than double to 1.4 million. The health social costs are currently at a critical level with all the evidence showing accelerated demand.

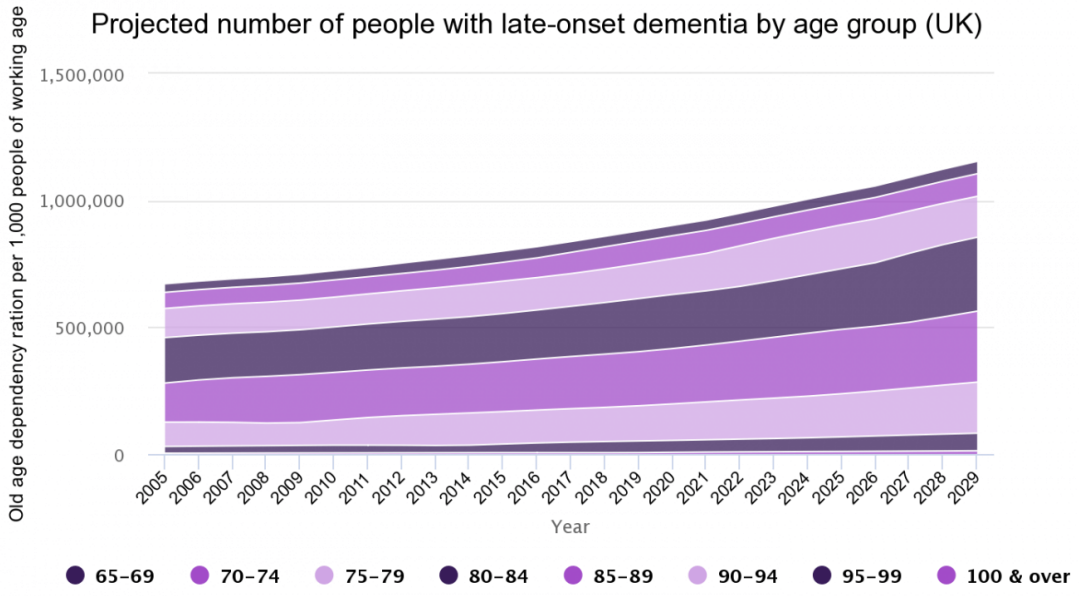
Demographic change will drive significant growth in the number of people with dementia, even though the percentage of older people developing some types of dementia (particularly vascular dementia) may decline as a result of reductions in hypertension and other risk factors (Snell T, Wittenberg R, Fernandez JL, Malley J, Comas-Herrera A, King D, **2011**).

Research suggests that approximately one in four 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. The cost of dementia will rise by 61 per cent to £24 billion by 2026 (at 2007 prices), with most of this cost being met by social care and by individuals and families rather than the NHS (McCrone P, Dhanasiri S, Patel A, Knapp M, Lawton-Smith S, **2008**).

Harrow has to look at ways of developing effective preventive/management interventions that could offset some of these significant costs in view of its local fiscal challenges.

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 is currently estimated to cost £26 billion to the society more than the cost of cancer, heart disease or stroke and this is expected to triple by 2040. 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
- GPs 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 Minister'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 on four core themes:

- Risk reduction
- Health and care
- Awareness and social action
- 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 calculator 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 encourage to develop Dementia Friendly Charters and work with business leaders to make individual commitments and also become dementia friendly.

Harrow Local Authority undertook a Dementia Friendly Housing review to:

- develop a greater understanding of what constitutes 'dementia friendly' housing;
- develop a greater understanding of and clarity around whether current housing provision within the borough meets the needs of residents aged 65 and over, diagnosed with dementia, or those that could develop the condition in the future;
- identify measures that the Council could implement to help meet future housing needs and in doing so, identify what overall steps Harrow Council can take towards becoming more dementia-friendly.

Dementia Research will become a career opportunity of choice with the UK being the best place for Dementia Research. An international dementia institute is to be established in England and increased investment in dementia research will be encouraged. https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020

LOCAL CONTEXT

Statutory Dementia Service in Harrow

Harrow council has a statutory duty to carry out a community care assessment, which will assess 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.

The council has equipped various voluntary sector workers and volunteers in terms of supporting people with dementia through training programmes. These courses are person centred and also a practical way of sharing knowledge and raising awareness of dementia amongst carers and within the voluntary sector.

Harrow Memory Services

The Memory Assessment Service (MAS) as part of Central and North West London NHS Foundation Trust (CNWL) provides a comprehensive assessment of an individual's memory, ensuring that if dementia is an issue a diagnosis is given as soon as possible. Once a service user has been diagnosed, the services can help to support the individual in coming to terms with their diagnosis and sign-post to agencies for post diagnostic support. 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 three 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.

Harrow's elderly population

There are 31,900 of older residents aged 65 and over. Harrow has one of the highest proportions of older residents aged 65 and over compared to other London boroughs at 15.2%. Old age is the most important risk factor for dementia and Harrow has the highest percentage of elderly residents of the 8 boroughs in the North West London sector. This is below the national average of 16.3%. Harrow is ranked 7th in London for the proportion of residents aged 65 and over. (ONS LSOA Mid-Year Estimates **2016**)

Percentage of population over the age of 65 – North West London Boroughs.

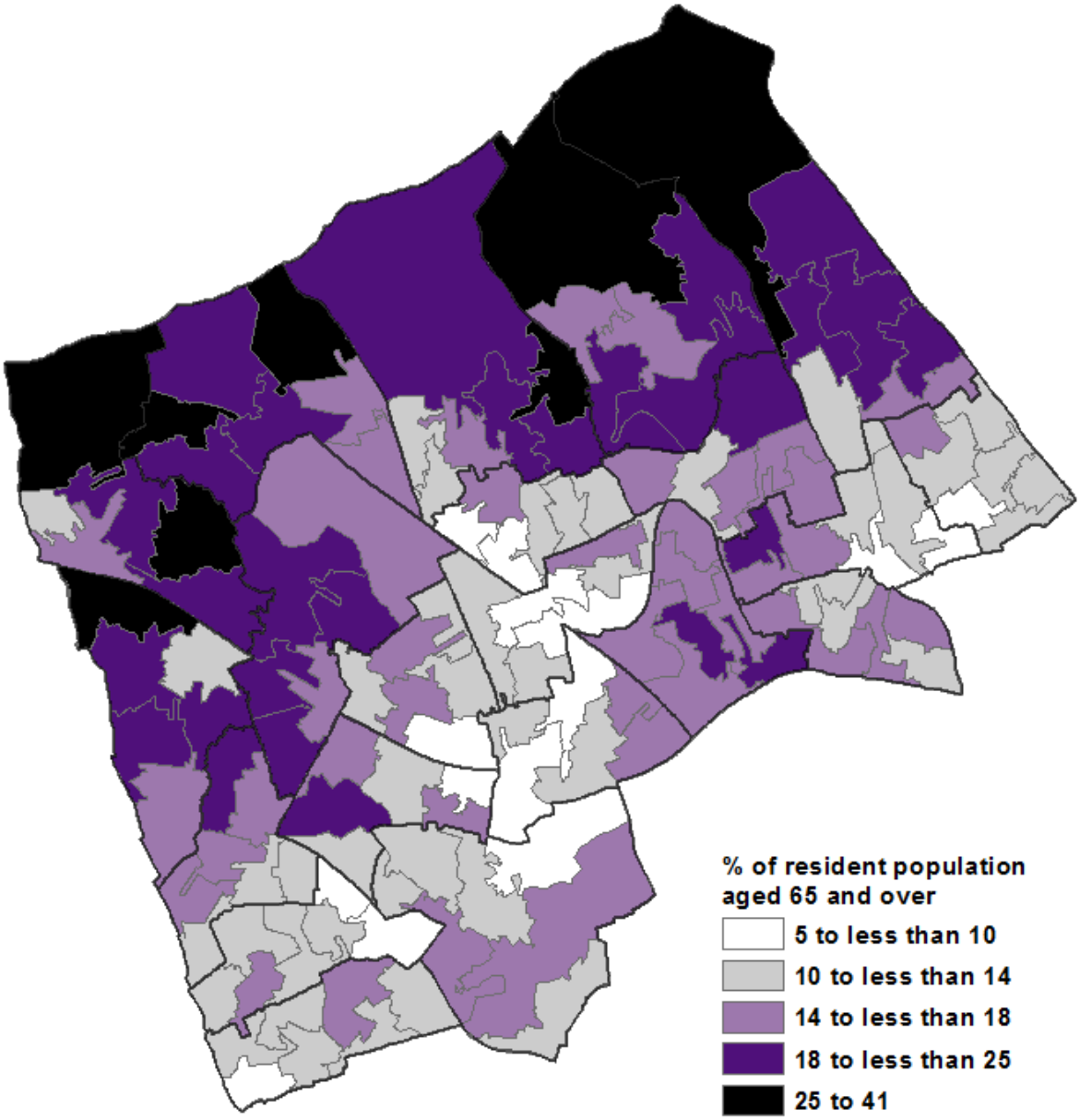
London Borough	**Percentage of total population over 65**
HARROW	15.2
Hillingdon	13.1
Brent	11.5
Kensington and Chelsea	14.9
Ealing	12.1
Westminster	11.8
Hounslow	11.5
Hammersmith and Fulham	10.5

Source: ONS projections - 2016

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 15.2% in 2016. High proportions of older residents live in the wards to the north. Stanmore Park has the highest proportion of people over the age of 65, with 23.5%. Roxbourne, Greenhill, Marlborough and Wealdstone have fewer than 12% of older residents over 65. The north of the borough has a higher percentage of elderly residents than the south and central areas of the borough (Source: ONS projections **2016**).

Percentage of elderly residents across Harrow's electoral wards.

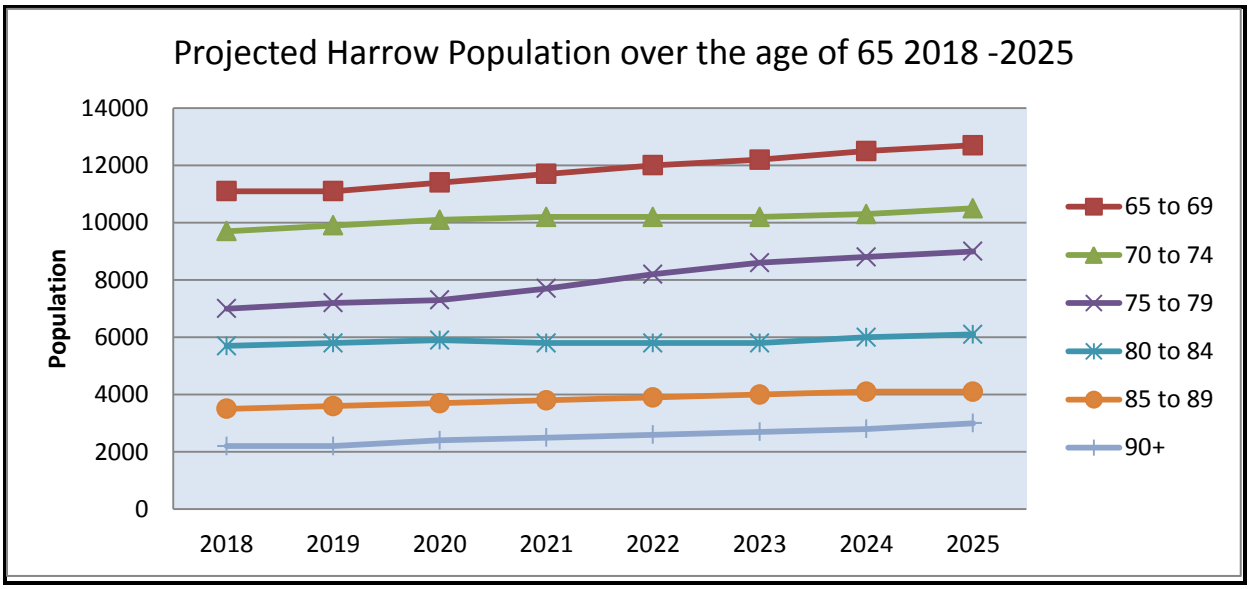
Residents Aged 65+ *Source: ONS LSOA Mid-Year Estimates (2016)*



- Harrow is ranked 7th in London for the proportion of residents aged 65 and over
- 5.2% of Harrows residents are aged 65 and over, 12% (4034 residents) higher since 2011
- Source: Harrow vitality profile 2017-2018

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 on the number of people with dementia



Source – GLA intelligence Unit- Released in July 2017

Estimated Dementia Prevalence (65+ only) NHS England Dementia Rate Denominator

July 2018	**Monthly Dementia Diagnosis Rate Indicator**	**Sum of Dementia Registers (65 + only) latest available Numerator**	**Estimated Dementia Prevalence (65 + only) CFAS II Denominator**
England	67.8%	441,626	**651,772**
London	70.8%	47,863	**67,617**
NHS Brent CCG	74.9%	1,846	**2,464**
NHS Central London (Westminster) CCG	73.4%	1,044	**1,422**
NHS Ealing CCG	76.1%	2,211	**2,904**
NHS Hammersmith and Fulham CCG	66.8%	839	**1,256**
NHS Harrow CCG	63.0%	1,589	**2,524**
NHS Hillingdon CCG	66.9%	1,814	**2,711**
NHS Hounslow CCG	71.1%	1,469	**2,065**
NHS West London CCG	75.7%	1,338	**1,767**

(Source: NHS England **July 2018**)

Dementia cases recorded on the GP register

In July 2018, 1,589 people aged 65 and over had been diagnosed with dementia. It is estimated that 2,524 people are living with dementia in Harrow. When applying the Dementia Diagnosis Rate shows Harrow as 63.0%. The denominator used estimates there are 2,524 patients currently living with dementia in Harrow. This forecast suggests there are over 935 people with dementia in Harrow who have not yet been diagnosed, or whose condition is not known to their GP. (Source: NHSE July 2018).

Estimated prevalence of late-onset dementia in Harrow by age group

Age group	Estimated prevalence of dementia in Harrow
Over 65 years of age	1 in 14 people
Over 80 years of age	1 in 6 people
Over 90 years of age	nearly 1 in 3 people

Source: Mental Health Observatory

Consensus of Estimate of population prevalence of late on-set of dementia

Age in Years	Female	Male	Total
65-69	1.8%	1.5%	1.7%
70-74	3.0%	3.1%	3.0%
75-79	6.6%	5.3%	6.0%
80-84	11.7%	10.3%	11.1%
85-89	20.2%	15.1%	18.3%
90-94	33.0%	22.6%	29.9%
95+	44.2%	28.8%	41.1%

NHSE – May 2018

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

The prevalence of dementia in females over the age of 65 in Harrow is estimated as 8.2% compared to 6.1% for males. This equates to a total of 1458 females with late onset dementia in Harrow compared to only 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. However, even allowing for age, Alzheimer's disease is thought to be slightly more common in females than in males. One of the main reasons for the greater prevalence of dementia among women is the longer life expectancy of women (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 recognise. 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. They represent around 5% of the 850,000 people with dementia.

Prevalence rates for early-onset dementia in black and minority ethnic groups are higher than for the population as a whole. People from BAME backgrounds are less likely to receive a diagnosis or support, this is due to some cultural belief and the stigma associated with dementia.

Studies have shown that people with a learning disability are at greater risk of developing dementia at a younger age and that one in ten people with a learning disability develop early-onset Alzheimer's disease between the ages of 50 to 65.

One in ten aged 40-49 and one in three 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.

Population estimates for 2017 from ONS (based on the 2011 census). This is resident population.

White	Asian	Black	Mixed/ Other	Total
113,000	105,000	10,000	25,000	252,000
45%	42%	4%	10%	

https://data.london.gov.uk/dataset/ethnic-groups-borough

The number of people registered with Harrow GP practices aged 65 years or older: **38,892 people.** (Patient demographic services extracts for Sept 2018). This is **GP registered** population not comparable with the figures for ethnicity from ONS above.

The largest BAME group is of Indian ethnicity. Research has shown that the borough has the largest concentration of Sri Lankan Tamils in the UK as well as having the highest density of Gujarati Hindus in the UK. The borough is also ranked the 8th nationally for linguistic diversity in the Greater London Authority.

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 aged 65 and over is 37,701 equalling 15.2% of the total population.

Studies in South Asian communities in Britain have shown there is a sense of stigma and inadequate knowledge about dementia care. This poses a great problem with diagnosis. People tend to put off going to get a diagnosis and this is a big challenge in Harrow.

STRATEGIC IMPROVEMENT 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 hospital 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.

Integrated care operates through working collectively to a single contract, a shared and single set of outcomes to be delivered and single funding stream for the services delivered. Early results from parts of the country that have started doing this – 'vanguard' areas – are seeing slower growth in emergency hospitalisations and less time spent in hospital compared to the rest of the country. The difference has been particularly noticeable for people over 75, who often face a revolving door of emergency admission, delayed discharge and then hospital re-admission.

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 65's from a provider partnership. The intention is that this new model of care will be designed during September and October 2018, 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 of 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 2am over the next few months.

   The overall vision is for telemedicine to be available via 111 *6 in all older peoples care homes, whereby the 111 clinician will be able to complete a consultation as care homes will have access to a tablet device. This pilot will be tested first in a Brent care home with a Harrow care home being tested within 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 peoples 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. This pilot is due to commence by January 2019 and will initially run 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 and

Dementia awareness training for staff

Training and educating staff in Dementia Core skills will improve staff knowledge, skills, attitude and confidence and this can have a positive impact on those they provide care. The framework is a comprehensive resource to support health and social care staff, educators and carers who work with and care for people living with dementia. It sets out the essential skills and knowledge necessary for all staff involved in the dementia care pathway. Harrow CCG has commenced training for GP practice and would expect all staff that comes into contact with patients who have dementia to at least attain Tier (1).

Dementia Awareness: Summary of framework subjects

Subject	Tier 1	Tier 2	Tier 3
Dementia awareness	●	●	●
Dementia identification, assessment and diagnosis		●	●
Dementia risk reduction and prevention		●	●
Person-centred dementia care		●	●
Communication, interaction and behaviour in dementia care		●	●
Health and wellbeing in dementia care		●	●
Pharmacological interventions in dementia care		●	●
Living well with dementia and promoting independence		●	●
Families and carers as partners in dementia care		●	●
Equality diversity and inclusion in dementia care		●	●
Law, ethics and safeguarding in dementia care		●	●
End of life dementia care		●	●
Research and evidence-based practice in dementia care		●	●
Leadership in transforming dementia care			●

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

	Commitments for local focus in Harrow	**Delivery Plan**
1	Improved public awareness and understanding of the factors, which increase the risk of developing dementia and how people can reduce their risk by living more healthily. This should include a focus on health inequalities, a new healthy ageing campaign and access to tools such as a personalised risk assessment calculator as part of the NHS Health Check.	**June 2019**
3	People with dementia having equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be 6 weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia	**Done**
4	All Clinical Commissioning Groups and Local Health and Wellbeing Boards having access to improved data regarding the prevalence of dementia at local and national level and using this data to inform the commissioning and provision of services so that more people with dementia receive a timely diagnosis and appropriate post diagnosis support.	**Done**
5	An increase in the numbers of people of Black, Asian and Minority Ethnic origin and other seldom heard groups who receive a diagnosis of dementia, enabled through greater use by health professionals of diagnostic tools that are linguistically or culturally appropriate	**June 2019**
7	GPs playing a leading role in ensuring coordination and continuity of care for people with dementia, as part of the existing commitment that from 1 April 2015 everyone will have access to a named GP with overall responsibility and oversight for their care	**Done**
8	Every person diagnosed with dementia having meaningful care following their diagnosis, which supports them and those around them, with meaningful care being in accordance with published National Institute for Health and Care Excellence (NICE) Quality Standards.	**October 2019**
10	Increased numbers of people with dementia being able to live longer in their own homes when it is in their interests to do so, with a greater focus on independent living	**March 2020**

Views of Key Stakeholders

Harrow CCG undertook a Dementia RightCare 'Optimal Design Workshop' in September 2016. The feedback is included below which has informed delivery to-date and will continue to form part of the delivery plan going forward.

Dementia RightCare - Optimal Design Workshop Feedback from stakeholders event held on 7 September 2016				
	What, if any, changes were suggested by the group	**How should these suggested changes be implemented**	**What, if any, resources or information are required to implement suggested changes**	**What could be the impact of these suggested changes**
Preventing Well	▪ Early identification and risk scoring with 30's, 40's and 50's amongst high risk groups; ▪ Parkinson's, vascular risks; ▪ Current drugs of value? ▪ Better to focus on awareness and trigger points i.e. age group; ▪ Having a stand-alone memory service for people to independently access support where necessary.	▪ Wider stakeholder engagement and awareness raising; ▪ Strengthen link between research and practice; ▪ More support available in the community to tackle social barrier and stigma; ▪ Better support systems to promote healthy living and independence; ▪ Work with employers to raise awareness and enhance support system.	▪ More investment on awareness raising; ▪ High vascular risk prevention; ▪ More social care focus on prevention.	▪ Early identification; ▪ Early detection; ▪ Intergenerational work.
Diagnosing Well	▪ A link worker to support patients and carers throughout their journey e.g. highly skilled Admiral Nurses or Enhanced Practice Nurses to ensure a person-centred and individualised care; ▪ Memory Assessment Service to provide support pre and post diagnosis; ▪ More coordinated and integrated care involving social care and the voluntary sector in supporting patients and families with a dementia diagnosis; ▪ **Please refer to flowchart for suggested framework.**	▪ Develop care pathway for those at high risk of developing dementia; ▪ Develop and maintain robust process of communication amongst professionals; ▪ Recruit or make use of nurses to take on the role of link workers to coordinate patient care throughout their journey; ▪ Provide regular health checks and dementia screening for those at risk and with long-term conditions; ▪ Enhance existing Memory Assessment Service to support patients pre and post-diagnosis.	▪ Tailored training for healthcare professionals to raise awareness and understanding of the pathway; ▪ Create capacity to restructure the pathway; ▪ A system for health professionals to communicate, integrate and coordinate care; ▪ Better use and support from community services and voluntary sectors.	▪ Improved diagnosis; ▪ Early detection and more tailored intervention; ▪ Better support offered to patients and carers; ▪ Coordinated and person centred care and support provided; ▪ Improved value to the population of Harrow.

Living Well with Dementia and Planning ahead	▪ Use of Admiral Nurses for advice, practical and emotional support as early as possible; ▪ Integrate services and support available in the community; ▪ Information, advice and support more readily available to patients, carers and professionals; ▪ Mapped services and pathway to allow carers and professionals to navigate the care and health system; ▪ Involvement of carers and case manager in planning for the future and preparing for future eventualities; ▪ Advice and support available early enough to support patients' and their families to plan ahead and prepare for the future.	▪ Package of care/support agreed and formulated with carers and reviewed regularly; ▪ Care package coordinated by the care navigator; ▪ Care coordinated similar to the care principles of 'palliative care'; ▪ Develop and promote services and support in the community to help patients and carers feel valued and safe in society; ▪ Raise awareness of carers' rights and improve signposting to access legal and financial advice. ▪ Social services and health provide more coordinated care and support; ▪ Use of peer support i.e. patient or carers led; ▪ Enhance pathway to support carers' health and well-being.	▪ More widespread information about the resources and support available to patients and carers; ▪ A database or system that coordinate social care, health care and voluntary sector agencies. ▪ Support to facilitate access to appropriate services; ▪ Innovative models of care and more evidence base; ▪ More therapeutic models of care for patients and carers.	▪ A more positive journey for patients with dementia and their carers/ families; ▪ Carers and patients receive the support they need at the right time; ▪ Reduced levels of stress and worries for patients, carers and families; ▪ Patients and carers feeling more in control of their lives and condition; ▪ Higher number of people accessing appropriate support; ▪ Improved well-being of patients' and their carers and families; ▪ Possible reduction on prescribing.
Supporting Well and Preventing and Managing Crisis	▪ A system analogous to Macmillan Cancer support where care and support is available from diagnosis through to palliative care.▪ Adopt Admiral Nurse model as shown to work well;▪ Care reviews to be triggered by events rather than annual;▪ Reviews best carried out by case manager to ensure continuity of care;▪ Proactively change care and support provided according to patients' changing needs and 'trigger events' such as admission into acute settings, change in social circumstances; co-morbidities;▪ 24/7 crisis hotline for family and carers.	▪ Develop way to identify trigger points for a change in care / management needs to be identified;▪ Education and support for patients, family, carers and professionals to help identify subtle trends and changes;▪ Carers supported to become partners in care;▪ Support people with dementia and their families and carers to live well with dementia;▪ Ensure family and carers' needs are addressed and support to ensure patient well-being;▪ Entry into service provision should be based on needs rather than a diagnostic label.	▪ Create capacity in the system to provide flexible care to support patients' changing needs and late diagnosis;▪ Training and education to carers and professionals;▪ A system for health and care professionals to communicate and coordinate care according to patients changing needs;▪ Nurses to coordinate patient care ;▪ Better use of voluntary sector and social services to provide support to patients and their families and carers.	▪ Continuity of care and support to patients and family carers;▪ Improved emotional and practical support offered to patients and carers;▪ Carers supported and better able to manage and prevent crisis admission.▪ Carers supported and better able to improve patients' well-being;▪ Tailored care and support provided according to changing needs of patients and carers;▪ Improved and timely access to appropriate services by patients and carers;

Dying Well with Dementia	▪ Risk stratification tool to identify multiple admissions and reduced levels of functioning; ▪ A first point of contact (i.e. 'Dementia Adviser' to carry out regular reviews, care coordination/navigation and emotional support; ▪ Access to menu of support/ability to refer; ▪ Personalised and flexible care plans owned by patients and carers with rights of access and determination between carer and patient clearly outlined; ▪ Proactive care plans that clearly describe agreed provision of care and support to empower patients and carer to achieve personal goals; ▪ Care plans to describe family and social situation and is used by the system; ▪ Emotional and practical support for carers post death.	▪ Regular review of need and care plan with single point of contact (i.e. 'Dementia Adviser' to foster trusted relationship; ▪ 'Dementia Adviser' to develop, manage and review patient/carer owned care plan and support patient and carers; ▪ 'Dementia Adviser' to identify when condition of patient deteriorates or circumstances change to adapt care approach and provide advice and first line emotional support to carers and families. ▪ Pilot Stafford and Cannock's 'Memory First' programme; ▪ Provide separate (and shared) support for patient and carer.	▪ 'Dementia Adviser' to have dementia expertise; local knowledge and awareness of services including cross boundary, cultures and communities; ▪ Alzheimer's Society to provide evidence and information; ▪ Support system that prepare families and patients for end of life and build early plans, some of which would commence at diagnosis (linked with care plan and 'Dementia Adviser') ▪ End-of-life support and education for people with dementia and carers;	▪ Possible reduction in hospital admissions; ▪ Improved support offered and personalised care to patients and carers; ▪ Reduced demand on primary care; ▪ Prevent unnecessary clinical interventions; ▪ Better experience and outcomes for patients and carers;

<u>Where we are now</u>

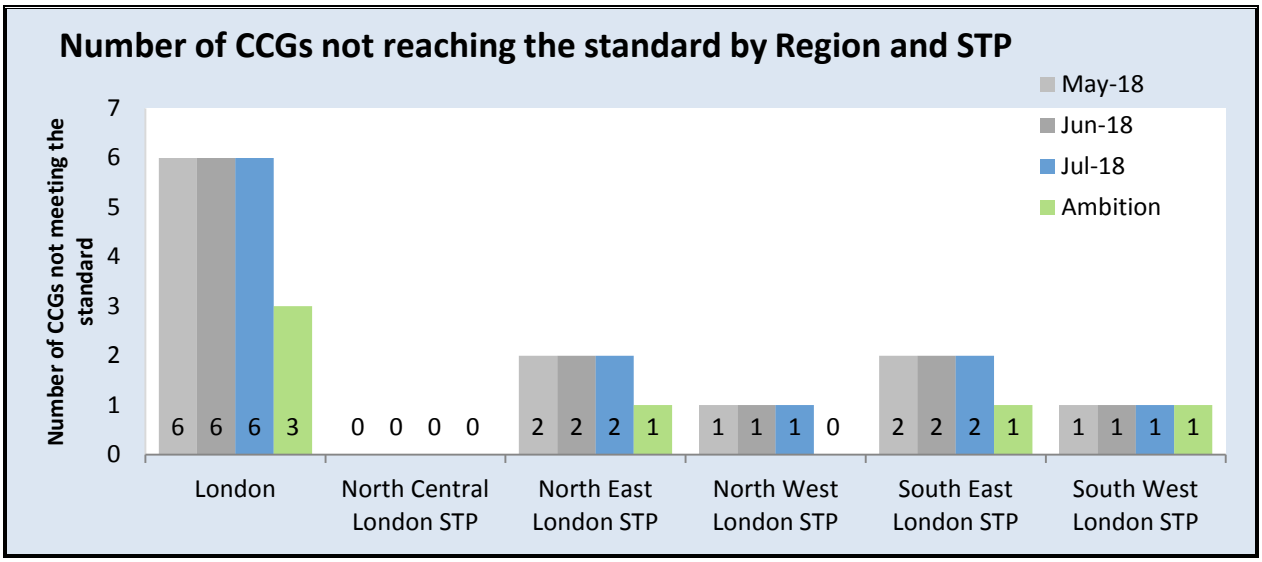
Significant progress has been noted since the 2010 to 2015 strategy and they are as follows:

- Partnership working between the Memory Assessment Service (MAS), GP's, Acute Hospitals, and through referral agencies
- Sign Posting to Voluntary and Community Sector Organisations resource funded and non-resource funded support services in Harrow
- Weekly Local Authority engagement with older people services, CCG and Acute Mental Health services to prevent 'delayed transfers of care' (DToC)
- Co-located social worker based in the team
- A pre-screening tool has been designed for Nursing Home staff to review their patients where dementia is indicated but not diagnosed. This will allow a more focused approach for the MAS and GPs. The screening tool has been shared with the Local Authority to deploy in partnership working with Nursing Homes
- MAS service already participating in reviews of patients in nursing homes
- CNWL and the MAS are training all their staff; 'Make every contact count'
- Harrow Patient Participation Network and CCG Engagement Team are working together to develop a strategy for public engagement to raise awareness and to de-stigmatise dementia.
- 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

We are doing a lot of work in terms of addressing the stigma and cultural taboo associated with dementia where many families are reluctant to seek help and miss out on health and 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.



Harrow is on trajectory to meet the Dementia Diagnostic Rate Target of 67% by December 2018.

Harrow CCG Dementia Diagnosis Improvement Plan

- Performance management driven by the Executive team including the Chairman and MD
- Clinical Director for Mental Health has been involved at every level in driving the requirement to increase diagnosis
- Clinical Director leads meetings held with CNWL (MAS) in trying to drive up numbers being diagnosed
- MD engaging with VCSO's including Harrow Patient Participation Network to cascade wider awareness and to seek their support in engaging with users and carers
- Areas of underperformance reviewed regularly at the MDs/CDs where

discussions to assess any additional approaches that can be taken and to quantify the impact of any actions already taken.

- Dementia performance is also discussed at the Finance Recovery Operation Group under the assurance section
- Reports including Dementia performance is reviewed at the Finance & Performance Committee
- Performance against all areas including Dementia is reviewed at the Senior Leadership Team

<u>CCG strategies to deliver the diagnosis ambitions</u>

- Practices have been asked to check the quality outcome framework (QOF) to ensure patients are recorded correctly.
- The message has been repeated in other formats to all GP Practices during 2018
- Harrow CCG is in the process of using an EMIS Specialist to deep-dive ensuring effective cleansing of all registers. Monitoring will be undertaken practice by practice.
- In the letter to GP practices Harrow CCG suggest; practices review all treatment cases on 'GP EMIS' where reversible medications (Acetylcholinesterase inhibitors) are being used for patient not diagnosed with dementia or review how they are being coded. In addition GPs are asked to review their coding for cognitive impairment as in some cases these can be coded as 'Dementia unspecified' (Read Code: Eu02z).
- Harrow CCG will follow up the cleansing with the joint harmonisation work in collaboration with CNWL MAS
- GP practices will receive requests from Harrow CCG to maintain compliance fortnightly, then monthly dependent on outcome
- CNWL (MAS) are undertaking a reconciliation of all diagnosed cases with GP practice record.
- The CCG is supporting CNWL MAS with additional admin staffing to deliver this initiative.
- On completion this should form the basis of a full and 'live' Dementia Register for Harrow
- Harrow MH Commissioners, CNWL, London Borough of Harrow and the Voluntary and Community Sector are developing a strategy for post-diagnostic support. The Dementia Strategy (2018-2020) is due to go to the Harrow Health and Social Care Scrutiny Committee in October 2018
- Support to deliver this is being requested through Faith Groups, Community Networks, Harrow Carers, Harrow Mencap, Harrow Mind, Harrow Patient

Participation network, and Harrow Association of Somali Voluntary Organisations

- Harrow CCG has commissioned an EMIS specialist experienced in uncovering undiagnosed cases to support GP practices with increasing their dementia diagnosis rate.

CONCLUSION

The purpose the strategy is to provide a framework for creating and empowering dementia environment for the people living with dementia and their families. The focus is to help people with dementia needs feel in control of their lives, feel valued and to also help carers feel satisfaction in charge of the disease what they accomplish in care.

The strategy will be subject to scrutiny where potential gaps in the pathway may be identified, as they often are when users, carers, friends and family provide personal stories and experiences. Learning from such comments will help to improve diagnostic and post diagnostic health and social care support for dementia.

The local and national strategic vision is set out to be achieved in the document. Aligning the action plan to deliver it and providing the evidenced will be achieved through partnership working between all stakeholders. Health and Social Care will take the lead as accountability will be monitored through their regulators.

Implementation of the plan has started and the new NICE guidance will provide a measurable framework and toolkit to deliver the best dementia care and support.

This strategy supports the national dementia plan and we are committed to improving dementia care in Harrow.