DEMENTIA STRATEGY FOR HAMMERSMITH AND FULHAM

2021 - 2024



All Ability Cycling Hub on Fridays - For Brian, CIC with Bikeworks

Living Well

I am always touched by incredible gestures of humanity frequent acts of kindness no matter whether it's shady or sunny achieving little goals day by day making sure I take time to smell the roses feel the glow on my body being believed and supported the difference between listening, and hearing fight ignorance, have patience, remove burden.

Be the best ally possible: love what is; stand up for empathy

Excerpt from 'Living Well' – poem co-produced with H&F residents for Dementia Action Week 2021 - Dan Simpson, Poet in residence, Imperial College London

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1. Foreword

Dementia affects more and more people each year. Many of us already have experienced the impact that dementia can have on people we know and on our families.

This co-produced Hammersmith and Fulham Dementia Strategy reflects the views and experiences of people living with dementia and their carers, and those of the public, private, voluntary and community sector services supporting them (our 'dementia community').

Priorities identified by our dementia community include a range of dementia specific and dementia inclusive activities that give choice and control, reduce social isolation, and promote equality: clear accessible information about how to get services and support and for the borough to become a Dementia Friendly Community.

In order to respond to the priorities identified, it is imperative that Health and Social Care, in partnership with other services, have a clear strategy to support people living with dementia and their carers, now and in the future. The new H&F Integrated Care Partnership (ICP) provides the framework, overarching governance and accountability for the Council and the NHS to collaborate with the local community to make this happen. We are encouraged that that the additional needs of people living with dementia and their families are informing the work across the ICP Campaigns.

Co-production will be at the core of the work of the proposed Dementia Partnership Board, which , we anticipate, will have oversight of implementation of the recommendations contained within this strategy.

We would like to thank all those individuals, groups and organisations who have given their views and helped to shape this strategy, and particularly those represented on the Dementia Strategy Task and Finish Group.



Stuart Downey – Chair of H&F Dementia Action Alliance (DAA) and Partner - TWM Solicitors)

2. Executive Summary

This is Hammersmith and Fulham's first Dementia Strategy. It was co-produced with people with dementia, their families and carers and identifies the improvements needed to the services and support they receive. Dementia is a disability and hence we have aligned our co-production to the H&F Council's Disabled People's Commission 2018.

The aim of the strategy is to address the additional needs of the dementia community and the gaps, sufficiency, affordability, and quality of services as identified by our residents with dementia and their families, carers and the services supporting them.

The Dementia Task and Finish Group has gathered quantitative data available on dementia locally, regionally, and nationally, undertaken surveys with residents with dementia, their carers and families, stakeholders, and businesses, and reviewed where we are now and how we need to improve services and support in Hammersmith and Fulham to become a Dementia Friendly Community.

We have set out key recommendations which will inform the work of our proposed new Dementia Partnership Board to develop an implementation plan and have oversight of progress in improving the wellbeing of our Hammersmith and Fulham dementia community.

Our data, surveys and co-production identified eleven local priorities:

- 1. Early and accurate diagnosis within clearly understood timeframes
- 2. Clear and accessible information about how to get services and support
- 3. People affected by dementia must be treated with dignity and respect and be offered opportunities for good quality of life throughout their condition
- 4. Good availability and choice of day services, short breaks and overnight respite to support people with dementia, their families and carers
- 5. Multi-disciplinary coordination between services, with improved communication and cooperation between services and with people with dementia, their carers and families
- 6. Continuation of support and care for people with dementia, their carers and families, including the sensitive planning and provision of end-of-life care
- 7. Services must meet the real, as opposed to assumed, needs of people with dementia and their carers and families
- 8. A network of peer-led support groups across H&F for the recently diagnosed, for families and carers, for people who have been living with dementia and for carers living with bereavement
- 9. A range of dementia-specific and dementia-inclusive activities that give choice and control, reduce social isolation, and promote equality
- 10. Ensure that the health and social care workforce meets core competencies around dementia and that family carers are offered training to meet their needs
- 11. Hammersmith and Fulham to be a Dementia Friendly Community.

These priorities in turn informed our nine recommendations:

- 1. That a **Dementia Partnership Board** be established to oversee an implementation plan, with representation from the NHS, H&F Council, the Voluntary and Community Sector and people with dementia, their carers and families.
- 2. That the Dementia Partnership Board **co-produces** services and support for people with dementia and their carers from all our diverse communities, including those who are Black, Asian and minority ethnic, in order to tackle systemic barriers to early diagnosis and the accessibility and adequacy of services.
- 3. That the Dementia Partnership Board prioritises improving the **Dementia Diagnosis Rate** for Hammersmith and Fulham, working closely with GP surgeries, Primary Care Networks, the Older Peoples Mental Health Service (OPMHS) and all professionals and front-line staff in the NHS, Social Care and the voluntary and community sector.
- 4. That the Dementia Partnership Board establishes a **Data Working Group** to understand better the profile of the residents on the Dementia Register, the changing demographics of Hammersmith and Fulham and the diagnosis patterns across GP surgeries.
- 5. That the Dementia Partnership Board develops a **Dementia Communications Plan** which includes a printed Dementia Guide and online local services and support. This will include training for staff and volunteers to signpost and refer to services, developing the confidence and practice of the network of professionals, carers and volunteers working with people with dementia.
- 6. That the Dementia Partnership Board **reviews and develops the dementia pathway**, that is the continuation of support and care for people with dementia and their families, including end-of-life care. A key focus will be creating a range of dementia-specific and inclusive activities that give residents choice and control.
- 7. That the Dementia Partnership Board promotes **multi-disciplinary practice** and keyworkers to support people with dementia and their carers at the earliest opportunity to ensure their issues do not escalate, with a specific focus on residents aged over 65 living alone.
- 8. That the Dementia Partnership Board co-produces a **Dementia Workforce Development Strategy**, which establishes core competencies including empathy and compassion.
- 9. That Hammersmith and Fulham progress towards becoming a 'Dementia Friendly Community', encouraging local statutory and voluntary organisations and businesses to improve the health and wellbeing of people with dementia and their families.

3. Introduction

This strategy sets out how significant improvements can be made to the planning, commissioning, delivery and review of local services so that people with dementia and their families are better supported. Our hope is that it will prove to be an important milestone in improving services for residents with dementia and their family and carers in Hammersmith and Fulham.

The H&F Dementia Strategy Task and Finish Group (DSTFG) initially convened in March 2020 as a group of stakeholders concerned about the impact of Covid-19 lockdown restrictions on elderly residents with cognitive issues.

The DSTFG has representation from H&F Dementia Action Alliance (DAA), the Alzheimer's Society, For Brian CIC, Carers Network, Nubian Life, Elgin Day Centre, the Older People's Mental Health Service (OPMHS) Clinic, the GP Federation and with support from H&F Adult Social Care.

The group began by identifying the key issues in the borough's Dementia Care Pathway and focusing on the sufficiency and quality of local services with the aim of ensuring the best quality of life for people with dementia, their carers and families.

The active engagement of the new H&F Integrated Care Partnership (ICP), which brings together the Council and NHS, will be essential to achieving the strategy's aims, working with local dementia partners. We much appreciate the support we have had from H&F Council, H&F Clinical Commissioning Group and the ICP to date.

4. Some facts about Dementia

The Alzheimer Research UK's Dementia Attitude Monitor has revealed that more than half of the UK public (52%) know someone who has been diagnosed with a form of dementia, typically a family member such as a grandparent (15%) or parent (11%).

Dementia cannot be viewed singularly as a mental health issue. It is a disability and one typically with multiple comorbidities impacting on the additional needs of the person with dementia, their families and carers.

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. A person with dementia may also experience changes in their mood or behaviour, with greater sensitivity to noise and visual misperceptions, hallucinations, and delusions.

Dementia is caused when the brain is damaged, such as by Alzheimer's disease or a series of strokes. Alzheimer's disease is the most common cause of dementia. Other common types of dementia are vascular dementia, mixed dementia, dementia with Lewy bodies and frontotemporal dementia.

Dementia is a long-term progressive condition. As such, it causes changes that are often small to start with, but which can become severe enough to affect daily life for someone

with dementia. This progression will vary from person to person and each will experience dementia in a different way.

People with mild dementia will be able to continue to live actively and independently, with minimal support and adjustments. People with moderate dementia will need more support with the tasks of daily living and social engagement. People with severe dementia will need full-time support, often including nursing care, for them and their families to live well. ¹

Risk factors for dementia include:

- Ageing
- Gender (higher prevalence amongst women)
- Ethnicity (different ethnic communities experience dementia differently)
- Cardiovascular factors (Type 2 Diabetes, high blood pressure/cholesterol levels and obesity)
- Other medical conditions (e.g., Parkinson's, Multiple Sclerosis, HIV)
- People with Down's Syndrome and Learning Disabilities
- Genetics (for some young onset dementias)
- Medications that are high on anticholinergic activity
- Hearing loss, untreated depression, loneliness or social isolation, excessive alcohol misuse and a sedentary lifestyle

There is currently no cure for dementia. However, there is compelling evidence that a healthy lifestyle can help reduce an individual's risk of developing dementia by as much as 40%. It can also help prevent cardiovascular diseases such as stroke and heart attacks, which are themselves risk factors for vascular dementia.

4.1 The local picture in H&F

Before we know how best to offer treatment and support to people with dementia in Hammersmith and Fulham, we need to understand how many people in the borough have dementia, how severe it is and other factors which might lead us to tailor care to meet specific needs of our communities, such as ethnicity, where people live and whether they have people to care for them.

We set out some data below. While this is revealing, it is not sufficient and the picture it paints is partial due to a number of factors as below.

- The data is subject to different recording, categorisation and protocols.
- While we have some data about referrals to Older People's Mental Health Service (OPMHS), we lack data about those referred who received a diagnosis, how long the diagnosis took, how old these people are, what stage or subtype of dementia they have, where they live (for instance in a care home or independently) and in which ward or community they are active in H&F.
- Data on risk factors for dementia is skewed due to Babylon GP at Hand's

registrations from across London.

 We lack current data about the ethnicity and nationality of people with dementia who are registered with GPs in H&F.

Our recommendations address how data around dementia can be improved.

4.2. What the data for H&F tells us

As of July 2021, it is estimated that there are 1,337 Hammersmith & Fulham residents aged 65 years and over living with dementia². According to a report published by the Care Policy and Evaluation Centre (CPEC) at the London School of Economics and Political Science (LSE), it is estimated that the number of people estimated to have dementia in Hammersmith & Fulham is expected to rise by 42% to 1,900 people living with dementia in 2030³.

However, in H&F, as of July 2021, there are 770 people over the age of 65 with a recorded diagnosis of dementia (representing 3.5% of the total H&F population in the 65+ age group). This is the lowest number of people diagnosed with dementia so far this year in any London borough and also the second lowest recorded dementia prevalence of any London borough after Newham.

In Hammersmith & Fulham, the dementia diagnosis rate in the population over 65 years is 57.6% as of July 2021. It is lower than the national diagnosis target for dementia which is 66.7%. In order to reach the national target, Hammersmith & Fulham would need to diagnose 121 more people. This diagnosis rate is the second lowest of all London boroughs.

Dementia diagnosis in H&F is unacceptably low; local residents are not receiving equity of diagnosis as in other boroughs with Mental Health services provided by West London Mental Health Trust (the dementia diagnosis rate for Hounslow is 65% and for Ealing 68.7%)

In H&F, 36 people under 65 years have a recorded diagnosis of dementia and these 'Early Onset' cases of dementia account for 4.5% of all recorded dementia diagnoses. These residents require a different set of support interventions, with Care Plans reflecting that the person with dementia can also be employee, 'breadwinner' or parent or even carer for another family member.

Of the 1,337 estimated dementia population in H&F in 2020, 58.2% were estimated to have severe dementia, 27.3% moderate dementia, and 14.5% mild dementia. The sharpest increase is estimated to occur among those who are diagnosed as having severe dementia

² NHS Digital. Recorded Dementia Diagnoses July 2021. [Online]. Available farom: https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/july-2021

³ Wittenberg, R,. Available from: https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

By 2030, it is estimated that of those people living with dementia in H&F, 63.1% will have severe dementia, 23.9% will have moderate dementia and 12.8% will have mild dementia. As our population of older persons get older, so too will their dementia disease advance, requiring more costly care.

As of 2020, 32% of all H&F residents over 65 live alone, equating to 6744 residents. It is likely that many of these residents are at increased risk of getting dementia due to the effects of isolation. Even more critical, are the residents who have developed cognitive issues who may not be known to the Local Authority or to the NHS, and the Dementia Partnership Board must engage H&F Housing and Registered Social Landlords to coordinate support.

In H&F there is an unusually high recorded prevalence of dementia amongst Black, Asian and Minority Ethnic (BAME) communities. Nationally, these account for 3% of people with dementia, whilst in H&F in 2019, of those with a recorded dementia diagnosis who recorded ethnicity, 30% were from a Black Caribbean, Black African, Asian, and other ethnic backgrounds.

Everyone has a right to equity of diagnosis regardless of their local ward or GP and to the very best care and support. It is vital that dementia services in H&F become as accessible as possible by understanding the psychosocial dimensions and cultural factors specific to each community group.

There were 970 emergency admissions into hospital in 2019/2020 where dementia or Alzheimer's is mentioned in the diagnosis code. This equates to a rate of 4,893 dementia admissions per 100,000 population.

Further analysis of frequent users, some who live alone, will clarify residents with dementia for whom there may be more appropriate care. The Dementia Partnership Board will oversee the collaboration across Health, Social Care, and the Emergency Services.

Improving the quality of our data in all aspects of our forecasting, planning and delivery of dementia services and support is a key recommendation going forward and will be central to the work of the proposed Dementia Partnership Board. We know that this is a priority for West London Trust as part of their transformation of Older People's Mental Health Services.

5. Co-production

"Co-production (working together) means that Disabled residents and decision makers are working together in an active way to plan, design and review policy and services that affect our lives, to get rid of the barriers we face" – **H&F Council's Independent Disabled People's Commission, November 2017**

Using the Disabled People's Commission model of co-production and following the DEEP (Dementia Engagement and Empowerment Project, the network of Dementia Voices), we have developed our understanding of the experience of people with dementia, of their carers and families and of the people who support them through:

Regular meetings of the Dementia Strategy Task and Finish Group

- Conversations with people with dementia and with their carers and families as to how they experience local services and support
- Four online surveys for people with dementia, carers, stakeholders and businesses to establish what works well locally, where there are gaps and what needs to be improved

Between November 2020 and March 2021, we utilised the Council's online survey software (Citizenspace) wherever possible to harness the views of all our H&F dementia community. As we realised this would not be accessible for many residents, H&F Dementia Action Alliance, Alzheimer's Society, For Brian CIC, Elgin Close Resource Centre and Carers Network also undertook face-to-face and phone conversations.

The surveys were communicated via our respective Dementia stakeholders, and for businesses via the Council's Economy Team business newsletter.

We received 135 responses in total:

- 52 responses from organisations and services supporting people with dementia and their carers/families
- 10 responses from business
- 28 from people with dementia
- 45 from carers.

H&F Dementia Action Alliance, Carers Network and H&F Council analysed the responses and captured the 11 highest scoring priorities identified by people with dementia, their carers and families and the people supporting them and local businesses. We have also begun to map the current services and support available in order to identify issues around eligibility, accessibility, and sufficiency. The survey and this work informed our recommendations below.

6. What people with dementia, their carers and families and local stakeholders told us were their priority issues to be addressed.

Priority 1: To obtain an early and accurate diagnosis within clearly understood timeframes

"Starting with a personalised dementia diagnosis – age and stage appropriate: we want person-centred care" – Person living with dementia

It needs to be clear to residents and to all professionals working with older people, as well as those under 65 with memory challenges, that it is important to diagnosis early to allow, for example, families to plan care, support, and finances, and to continue to manage symptoms in order to continue to live independently longer.

The existing system relies heavily on people self-identifying symptoms and presenting for medical diagnosis. This means that people who do not identify their symptoms at an early stage or those who do not wish to either receive a diagnosis or engage with statutory services, can miss out on vital support, information, and care planning.

Typically, the diagnosis process starts with a visit to the GP, who will do a preliminary assessment and organise necessary tests, followed by a referral to the Memory Clinic (aka Older Peoples Mental Health Service) to complete the diagnostic process.

As important, enabling a dialogue about people's concerns is part of developing a Dementia Friendly Community, providing the opportunity for people to enter a conversation, to ask questions and 'dip a toe in' without immediately initiating a diagnostic process.

Recommendations:

- 1.1 That we prioritise how we engage and co-produce dementia services with and for all our diverse communities, including those who are from Black, Asian and Minority Ethnic backgrounds, utilising our strong network of voluntary and community sector partners who have first-hand experience of systemic barriers to early diagnosis, of accessibility and adequacy of services and of engagement and trust in health and social care.
- 1.2 That we continue to work with H&F Dementia Action Alliance to improve community awareness and encourage open and ongoing discussions around cognitive decline, symptoms of dementia and changes in behaviour. It is essential that this engagement is authentic and inclusive, sensitive to the needs of all residents and delivered in a personcentred way.
- 1.3 That we educate the staff and volunteers in public and voluntary organisations and in the community (for example POPS Forum, Mutual Aid Groups, Libraries, Adult Education, and the Faith Forum) in order that they can recognise residents who might be experiencing cognitive difficulties, signpost them to services and support them in getting answers to their questions at the earliest opportunity
- 1.4 GPs are the 'front door' to the dementia care pathway and as such, must be part of Dementia Friendly Surgeries. We need to work with them to promote healthy living to mitigate the likelihood of getting dementia, identify dementia symptoms and share information with residents and their families about cognitive decline. Both culturally specific awareness and associated diagnostic tools will be key in building trust in the NHS.
- 1.5 That the Memory Clinic undertakes outreach with the community and with all of our dementia stakeholders to ensure that their service is widely promoted, understood and accessible to all the diverse communities of H&F and with a focus on increasing dementia diagnosis rates. Adult Social Care and NHS professionals must develop practice and policy around early identification of dementia and subsequent referrals to the Memory Clinic.
- 1.6 That the Dementia Partnership Board establishes a Data Working Group to focus on increasing dementia diagnosis rates in H&F through a better understanding of the profile of the residents on the Dementia Register, of the changing demographics of Hammersmith and Fulham and of diagnosis patterns across GP surgeries.
- 1.7 The Dementia Partnership Board will engage with the borough's Public Health team in reviewing the accessibility of services focused on preventing dementia to inform both future commissioning of services and to identify synergies with other Public Health priorities

Priority 2: Clear, accessible information about how to get services and support

"We want clear information about how to get help. Information must be available about services and how to find them. Printed materials are not always what's needed, but if published, they should be clearly written, simple and accessible" – Carer of person living with dementia

Some information and advice around support and services for people with dementia and their carers and families is held on each dementia stakeholder's website, this includes basic information about dementia services and provision is on the LBHF 'Living Independently' site. the Alzheimer's Society is also a source of practical information for people with dementia, their carers and the community.

However, the borough lacks a local accessible Dementia Guide which captures the range of support available across the borough in order that all resources can easily be found, professionals can signpost with confidence and people with dementia and carers can be supported at each stage with care and compassion.

We need to build on existing innovative partnerships around digital inclusion to provide information and advice in different formats and languages and to support people with dementia, their carers, and families to be proficient in accessing the internet.

Recommendations.

- 2.1 That a Dementia Guide is co-produced with residents with dementia and their carers and families. The guide should include the NHS health check dementia leaflet and be available in different languages and accessible to all our communities. It should explain each stage of the Dementia care pathway starting with pre-diagnosis, and explain treatment interventions and emotional and practical support available, with access-to-assistive technology
- 2.2 That the Dementia Partnership Board co-produces a Communications Plan. This would acknowledge that whilst some residents will access websites and use social media, others will not use technology. Printed information will need to be in different formats and languages to be accessible to all residents, with a 'drop-in' offer where questions can be answered face-to-face, with signposting as necessary
- 2.3 That, aligned to the recommendations in the Hammersmith and Fulham Older Peoples Commission (March 2019), highlighting the importance of partnership with the H&F Council Housing Team, Sheltered Housing providers, Tenants and Residents Associations, Wardens and Careline, we disseminate information on dementia services and support to the thousands of older residents H&F Council supports and accommodates.

Priority 3: People affected by dementia must be treated with dignity and respect and be offered opportunities for good quality of life throughout their condition

"We want people to realise there is a life still to be lived with a dementia diagnosis" – Person living with dementia

There is currently a limited offer of designated dementia activities commissioned by H&F Council or H&F CCG in the borough. We need to work together to ensure that we have sufficiency of the right kind of specialist services and support. Funding is required to produce a programme of activities which is both accessible and inclusive and which offers what is needed, even as the needs change over time.

All commissioned services must be inclusive to people of all cognitive abilities and from all our diverse communities, with support from staff who have participated in dementia awareness sessions.

Recommendations:

- 3.1 That the Dementia Partnership Board establishes governance which has coproduction at its core so that people with dementia, their carers and families are equal and valued partners in the planning, delivery, and review of improvements to services and support for all stages of the dementia condition.
- 3.2 That the Dementia Partnership Board should promote care as being a cycle of support rather than something linear every resident and carer's experience is different but the need to have high quality services, with strong underpinning safeguarding practice is important for everyone.
- 3.3 That the Dementia Partnership Board works with commissioners across the NHS and H&F Council to ensure they can evidence that they are inclusive, accessible and have a dementia friendly workforce.

Priority 4: Availability and choice of day services, short breaks and overnight respite to support people with dementia and their families and carers

"We want respite services to fit the daily schedule of the person with dementia or when the family needs it – not the other way around" – Carer of person living with dementia

As well as sufficiency of specialist services, we need further to develop day services, short breaks and respite to be flexible and person-centred. A consistent theme in our surveys was that the council must consider the needs of the family as to the frequency, time and duration of social care: the care package and the continuity of staff.

Recommendations:

4.1 That a review of all specialist dementia support services is undertaken, alongside the mapping of those mainstream services currently supporting people with dementia, to address the issues raised by residents with dementia and their carers and families as part of co-producing the Dementia Strategy

4.2 That the funders and commissioners represented on the proposed Dementia Partnership Board consider the sufficiency, quality, affordability and breadth of the existing dementia services and opportunities to bring extra resource and capacity into H&F.

Priority 5: <u>Multi-disciplinary coordination between services, with improved communication and cooperation between services and with people with dementia, their carers and families are considered.</u>

"Having access to one point of contact, instead of having to go from one service/agency to another and having to keep repeating myself" – Carer of person living with dementia

Although there are a number of professionals working with people with dementia and their families/carers, services often work in silos and are uncoordinated, wasting time and causing stress, particularly for carers.

We need to establish the principles of multi-disciplinary working at the earliest opportunity in order to coordinate and streamline care, support and sharing of information for all residents with dementia and not just those in crisis.

Given the increased prevalence of dementia among people aged 65+, a large number of whom live alone, we also need multi-disciplinary practice to support those who may feel socially isolated and lonely. Our local data and intelligence tell us that that some residents use the Police, Fire Service, A&E and Careline for non-crisis support when stronger multi-disciplinary working would ensure they received a person-centred response which mitigated against an escalation in their situation.

Recommendations:

- 5.1 That the multi-disciplinary working in Primary Care Networks (PCNs) is reflected in the planning and delivery of all support for those with dementia and for their carers and families, in particular for people with dementia living alone.
- 5.2 That the person with dementia, their family and carer are at the centre of the planning of care and support and that all support and all paperwork held by local services are co-produced to reflect that.
- 5.3 That services supporting people with dementia develop protocols which facilitate the appropriate sharing of data, minimise delays and avoid carers and families having to 'tell the story' over and over again.

Priority 6: Continuation of support and care for people with dementia, their carers and families, including the sensitive planning and provision for end-of-life care

"Post-diagnostic support should be continually available as and when we need it until end of life. GPs should be proactive in checking up. For example we want help to continue to be part of a group, so we want transport to get us where we want to go, with dementia friendly drivers" – Person living with dementia

There is currently no system in place to ensure that, at the time of diagnosis, people with dementia and their families are referred to a funded dementia service in H&F. After receiving a diagnosis (which is often a traumatic experience), some people never get around to registering with support services and lack the access to information and support throughout the dementia journey. Hence referral protocols and integration are required.

Added to this, the multi-disciplinary approach from diagnosis would inform better planning, support, and continuity with, ideally, one named professional (or key worker). This would enable families to build trust and confidence and enable professionals to plan care, respite and support effectively and efficiently.

Recommendations:

- 6.1 That the Dementia Care Plan and its vital role throughout the dementia pathway is clearly promoted and understood by the people with dementia, their carers and families and that sensitive management of end-of-life care is discussed and recorded at the earliest available opportunity and when people with dementia have mental capacity.
- 6.2 That post-diagnosis, a named worker is identified for continuity of support and to make a schedule of regular meetings between the GP and the person with dementia and their carers and family.
- 6.3 That in line with H&F Council's vision for Independent Living, people diagnosed with dementia are given choice and control as to where they live and the nature of the support they get for example, through active engagement by the Reablement Team, maximising digital technologies, and promotion of Personal Budgets all documented within the annually reviewed Adult Social Care Plan.

Priority 7 - <u>Services must meet the evidenced needs of people with dementia and their</u> carers and families as opposed to assumed needs

"Services centred around us like a menu, ones that fit our needs rather than what others think we want" – Person living with dementia

It is critical that in addressing the needs of our diverse communities we focus our work on and with those groups of people who lack trust in statutory services, some of whom may have increased risk of developing dementia due to ethnicity, age, lifestyle factors, sexual orientation, gender, and existing medical conditions.

Our on-going co-production with people with dementia, their carers and families will build our awareness of the intersectionality of these communities and how we can build on what services and support work well, and develop new services for those for whom existing ones are not a good fit.

Recommendations:

- 7.1 That the support offered to all who are referred to the Memory Clinic (OPMHS) is reviewed, acknowledging that support is not diagnosis dependent and those with Minor Cognitive Impairment should receive focused support from existing Dementia Link Workers in collaboration with dementia services.
- 7.2 That a referral protocol be established between the Alcohol Service and the OPMHS to support those at risk of getting alcohol-related dementia, building on the existing good practice protocol between the Learning Disability Team and the Memory Clinic.
- 7.3 That the Dementia Partnership Board works with expert bodies, such as the Social Care Institute for Excellence, when considering how best to support, for example, H&F's LGBT community and those with complex needs to access dementia services and support.
- 7.4 That the use of Advanced technologies, Assistive Technology and the range of equipment and adaptations is promoted to support independence and quality of life for people with dementia and their carers/families.

Priority 8: A network of peer-led support groups across H&F for the recently diagnosed, for families and carers, for people who have been living with dementia and for carers living with bereavement

"It was my dementia that I needed to understand. What better way to do that than with people who'd been through the same as me?" – Person living with dementia

It is widely understood that peer support groups improve wellbeing by providing both social and emotional support and practical advice

At each stage of the dementia pathway, there are new challenges for people with dementia and for their families and carers. Building on the services and support wrapped around the PCNs and existing dementia carer peer support groups, a variety of different peer support networks would help reduce isolation and loneliness, building a more resilient H&F dementia community.

Recommendations:

8.1 That the proposed Dementia Partnership Board explores funding opportunities and proposals to set up peer-led dementia support groups for all residents, including those recently diagnosed, as well as for families of people with dementia and for carers living with bereavement across Hammersmith and Fulham.

Priority 9: A range of dementia specific and dementia inclusive activities that give choice and control, reduce social isolation and promote equality

"Acknowledgement that medical information is only a small part of the picture. We want somewhere to go where we can be part of the community, where we feel we belong" – Person living with dementia

For people with dementia, their carers and families in H&F, getting out and about is a key ingredient in reducing their social isolation and maintaining their resilience.

Our surveys evidenced that:

- There is a need to offer a range of activities because not everyone likes to do the same thing
- It is important to minimise travel wherever possible, providing as much as possible within local areas in the borough and improving current transport arrangements
- People with cognitive challenges need a choice as they may prefer outdoor and physical activities in natural settings

Engaging in stimulating activities focused on shared group experiences is the cornerstone of social prescribing, improving wellbeing, reducing GP visits and delaying deterioration of health and risk of admission to care homes.

The commissioned 'offer' for dementia needs re-visiting to ensure organisations providing specialist support for people with dementia and their carers have a trained workforce and adequate funding and capacity to meet increased demand.

Recommendations:

- 9.1 That the proposed Dementia Partnership Board ensures (via self-referral or social prescribing link workers) a coordinated range of inclusive and accessible activities for people with cognitive impairment or a dementia diagnosis across the borough. This could include additional Memory Cafes in the north and south of the borough, an intergenerational dementia hub and a regular programme of outdoor and cultural activities, all increasing resident wellbeing and reducing patient medical visits
- 9.2 That H&F Council and CCG take a holistic approach in supporting people with dementia and their carers/families, acknowledging that being active, being creative and having a safe place to live are as important as receiving good quality health and social care.

Priority 10:. To ensure that the health and social care workforce meet core competencies around dementia and family carers are offered training to meet their needs

"We need trained staff with lots of patience, who know the person" – Carer of person living with dementia

Over 50 comments from stakeholders highlighted the importance of staff and volunteers receiving training pertinent to their role in supporting people with dementia, their carers, and families.

Stakeholders emphasised that training and development was not one size fits all and that:

- There are core competencies when supporting people with dementia and their carers and families which everyone should have
- Co-production and co-delivery of training and developed activities should involve residents and the organisations closest to and most experienced in working with those communities (for example, H&F Dementia Action Alliance, For Brian CIC, Elgin Close Resource Centre, Nubian Life and Alzheimer's Society).

Recommendations:

- 10.1 That a Dementia Workforce Development Strategy is co-produced and delivered with residents with dementia, their carers, families and with stakeholders and businesses. This will be delivered in local areas, harnessing the expertise of Skills for Care and H&F GP Federation's Community Education Provider Networks.
- 10.2 That Dementia Friends awareness sessions will continue to be used to increase understanding of dementia across H&F

Priority 11: Hammersmith and Fulham to be a Dementia Friendly Community

"The biggest problem I encounter is other people, we need more knowledge" - "Be kind and smile. If we look confused or anxious, ask if we're ok or need help" – Person living with dementia

In order that H&F becomes a Dementia Friendly Community, it will require the engagement of dementia friends from across public services and local business, the voluntary and community sectors.

H&F Dementia Action Alliance is working to raise awareness and maximise the impact of local organisations, services and businesses to support the dementia community; this includes organising Dementia Action Week in May each year.

Local businesses have a role to play in building the foundations of a Dementia Friendly H&F, demonstrating social responsibility, understanding their customers, and ensuring that their workforce is inclusive of people with dementia and carers.

As of June 2021, Hammersmith and Fulham has registered over 700 new "dementia friends" on the national Alzheimer's Society Dementia Dashboard.

Recommendations:

- 11.1 That an application for H&F to receive Alzheimer's Society accreditation as a Dementia Friendly Community is progressed and approved
- 11.2 That best practice is celebrated in becoming a Dementia Friendly Community. One such example is the Herbert Protocol, a national scheme encouraging carers of any age to compile information in advance of a vulnerable person going missing (promoted by H&F DAA in partnership with the Metropolitan Police's Mental Health Team to "help everyone stay safe").

.3 That LBHF and H&F DAA continue to encourage local statutory, volunta sinesses to become Dementia Friendly organisations.	ary and