



# Richmond Health and Care Dementia Strategy

A ten-year strategy 2022-2031



Public Health



# Contents

<b>Foreword from Lead Member and NHS Executive Place Lead</b>	<b>3</b>		
<b>Message from Director of Public Health</b>	<b>4</b>		
<b>Message from the Integrated Care Services Clinical Lead</b>	<b>4</b>		
<b>1 Background</b>	<b>5</b>		
1.1 Dementia	5		
1.2 About Richmond			
1.3 Describing the dementia system	8		
1.4 Assessing need	9		
1.5 Evidence underpinning the strategy	13		
1.6 Policy context	17		
<b>2 Developing the strategy</b>	<b>19</b>		
2.1 Strategic vision	19		
2.2 Aims, approach and principles	21		
2.3 Dementia Pathway priority phases	23		
2.4 Short, medium and long-term strategic objectives	24		
2.5 Co-production and engagement processes	25		
2.6 Governance and monitoring	26		
<b>3 The Dementia Prevention and Care Pathway</b>	<b>27</b>		
<b>3.1 PATHWAY PHASE 1</b>			
Preventing dementia and Reducing risk			
<b>3.1.1</b> What do we mean by prevention and reducing the risk?	27		
<b>3.1.2</b> Evidence underpinning the strategy	28		
<b>3.1.3</b> What we have achieved since the last strategy	29		
<b>3.1.4</b> Pathway mapping	29		
<b>3.1.5</b> Current services	33		
<b>3.2 PATHWAY PHASE 2</b>			
<b>Diagnosing dementia well</b>	<b>37</b>		
<b>3.2.1</b> What do we mean by diagnosing dementia well?	38		
<b>3.2.2</b> Evidence underpinning the strategy	39		
<b>3.2.3</b> What we have achieved since the last strategy	40		
<b>3.2.4</b> Pathway mapping	41		
<b>3.2.5</b> Current services	42		
<b>3.3 PATHWAY PHASE 3</b>			
<b>Support after dementia diagnosis</b>	<b>44</b>		
<b>3.3.1</b> What do we mean by support after diagnosis	44		
<b>3.3.2</b> Evidence underpinning the strategy	46		
<b>3.3.3</b> Pathway mapping	46		
<b>3.3.4</b> Current services	47		
<b>3.4 PATHWAY PHASE 4</b>			
<b>Enabling a fulfilling life with dementia</b>	<b>52</b>		
<b>3.4.1</b> What do we mean by enabling a fulfilling life with dementia	52		
<b>3.4.2</b> What we have achieved since the last strategy	52		
<b>3.4.3</b> Pathway mapping	54		
<b>3.4.4</b> Current services	55		
<b>3.5</b> overview of actions across the Dementia Prevention and Care Pathway	57		
<b>4 Emerging areas from Consultation</b>	<b>58</b>		
<b>4.1</b> Awareness, prevention, support and end of life care	58		
<b>4.2</b> Scoping a dementia hub	59		
<b>4.3</b> Digital technologies, social isolation and access	60		
<b>4.4</b> Supporting unpaid carers	61		
<b>Partnership</b>	<b>62</b>		
<b>Glossary</b>	<b>63</b>		
<b>Bibliography</b>	<b>64</b>		
<b>Acknowledgements and thanks</b>	<b>66</b>		

# Foreword from Lead Member and NHS Executive Place Lead

This ten-year strategy sets out our vision for Richmond residents affected by dementia, to enable them and their carers to live well, with the right support and care.

It builds on the achievements of our earlier strategy, and a refresh of this work which was carried out during 2020-2022.

Receiving a diagnosis of dementia can have a dramatic impact on a person and their loved ones. This strategy seeks to ensure that people have access to the support and care they need to help them continue to live as well as possible through the different stages of the condition.

The strategy doesn't stop there. We know that dementia can place unique emotional distress on families compared to other conditions, so providing support for unpaid carers is also an important focus. The strategy also acknowledges the need for improved service accessibility in the borough.

Local people, including those living with dementia and their families have informed the strategy which will be delivered through a partnership of health and care organisations operating in the borough, including the local authority, NHS, community and voluntary organisations.

There are five key strands to this work which are around prevention and improving awareness of dementia to the local community to diagnosis, care and support. Through our Dementia Friendly Richmond work, we will do all that we can to ensure that the borough is an inclusive one, where all residents affected by dementia are empowered and supported to live well.

We will also improve access to dementia services by strengthening the dementia practitioner team which works with people in the community. We will also do more to help people to navigate the health and care services in the borough, including an enhanced digital offer that provides accessible and easy to use health and care services for residents.

Due to the evolving nature of health and care services in the borough and beyond, the strategy will be refreshed half-way through its 10-year term, to ensure that local and national changes are considered and so that the strategy remains relevant for our residents.

Thank you to everyone who has actively engaged in the development of this strategy. We are excited to see the improvements that delivery of this strategy will lead to for all those affected by dementia, through our collective action.



**Cllr Piers Allen**  
Lead Member for Adult Social Care, Health & Public Health and Chair of Richmond Health & Wellbeing Board  
London Borough of Richmond



**Jo Farrar**  
Executive NHS Lead for Richmond,  
Chief Executive of Hounslow and Richmond Community Healthcare NHS Trust, and Kingston Hospital NHS Foundation Trust

## Director of Public Health

Dementia is a progressive disease often associated with complex health and social care needs; and based on current population projections; the need is expected to increase in Richmond. COVID-19 has uncovered how our disjointed care system can fail to support people affected by dementia .

The Richmond Dementia Strategy Refresh completed in 2019 started to address the gaps and opportunities to improve the dementia offer across Richmond and this strategy builds upon that . Building on the strategy and delivering a long term comprehensive dementia prevention, care and support offer for residents affected by and living with dementia remains a key focus for the London Borough of Richmond upon Thames alongside partners across the health and social care arena.

Alzheimer's Society states that "We believe, particularly in this time of recovery from the global pandemic, that a well-defined, clear and easily understandable strategy will lay the foundations for shaping future support and services in an area and, most importantly, improve the lives of people affected by dementia." Our Dementia strategy in Richmond embraces this ethos.



**Shannon Katiyo,**  
Director of Public Health  
London Borough of Richmond

## Clinical lead, Frailty and Personalisation

Dementia is a progressive, long term condition, which does not discriminate – affecting people regardless of their background, education and lifestyle. Every person with dementia is different and the effect the dementia will have on each individual is different.

Receiving a diagnosis of dementia can have a dramatic effect on a person and their friends and family. When people have dementia, they want to be able to access support to help them continue to live as well as possible through all stages of the condition. Putting the needs of the person with dementia at the centre of their care is important to provide the best possible outcomes.

With this Richmond Health and Care Dementia Strategy, the aim is to ensure Richmond is one of the best places for people with dementia to live.



**Dr Nerida Burnie,**  
Clinical Lead, Frailty and Personalisation,  
Richmond and Kingston

# 1

## BACKGROUND

### 1.1

## Dementia

Dementia is a progressive disease and people with dementia often have complex problems and symptoms in many domains of life requiring support for their health and social care needs. It is known that rates of dementia will continue to increase and that a significant number of our local population will either be at risk, require a diagnosis or need support and care to live well with dementia.

Dementia is the only condition in the top ten causes of death without a treatment to cure the disease. Aside from COVID-19 in 2020 and 2021, it has been the leading cause of death for women since 2015 in the UK. For men, it was the second leading cause of death and 8% of men died due to Alzheimer's disease and other dementias in 2015 in the UK.

As such, the scale of the challenge that dementia poses to communities, local councils and national governments should not be underestimated. It is for this reason that it has been identified as being the greatest global challenge for health & social care in the 21st century.

The majority of people with dementia are being supported and cared for by family members, often with age related health challenges of their own (43.9%). Current estimates suggest that there are 700,000 unpaid and family carers in the UK. The recent report from Alzheimer's Society "Left to Cope Alone: the unmet support needs after a dementia diagnosis" found that 61% of people affected by dementia did not feel they had received enough support in the last 12 months.

Funding for dementia services is also limited by cost and staff capacity, meaning services cannot consistently offer people with dementia the support they want and need.

## Types of dementia

Dementia is a neurological syndrome, and is an umbrella term which refers to a group of conditions (see box) which are characterised by the gradual and progressive loss of mental and cognitive ability (i.e. the ability to process thought), beyond what might be expected from normal aging. It affects an individual's day to day personal, social and professional functioning. Each subtype has slight differences in clinical features which predominate their presentation. In general, the symptoms experienced by people with dementia can be categorised as follows:

- Cognitive dysfunction including problems with memory loss, loss of language, attention, thought processes, orientation, calculation, and problem-solving.
- Psychiatric or behavioural problems such as changes in personality, emotional control, social behaviour, depression, agitation, hallucinations, and delusions.
- Difficulties with activities relating to daily living, such as experiencing problems with driving, shopping, eating, and dressing.



### Dementia sub-types

#### ■ Alzheimer's disease:

The most common form of dementia, accounting for approximately 60% of all dementia cases, Alzheimer's typically starts with impairment of episodic memory before affecting other brain functions.

#### ■ Vascular dementia:

The second most common cause of dementia, accounting for approximately 20% of cases of dementia in the UK. Vascular dementia typically presents with a stepwise deterioration in brain function, occasionally with localised weakness or reduction in vision.

#### ■ Dementia with Lewy Bodies (DLB):

The third most common form of dementia, accounting for approximately 15% of dementia cases. DLB is often associated with delusions, hallucinations and transient loss of consciousness. Occasionally DLB can cause difficulty mobilizing.

#### ■ Frontotemporal dementia (FTD):

<5% of cases of dementia are due to FTD in the UK. FTD is associated with gradual development of personality change and behavioral disturbance.

#### ■ Other:

There are other less common, forms of dementia

## 1.2 About Richmond

The London Borough of Richmond upon Thames is a prosperous, safe and healthy borough. It is composed of eighteen wards. The borough has five larger town centres: Richmond, Twickenham, East Sheen, Teddington and Whitton, as well as several local centres including Barnes, Kew, St Margaret's and Hampton Village. Richmond is the second smallest borough within Outer London.

Richmond has over 100 parks and open spaces and has plentiful heritage sites and attractions such as Kew Gardens, Hampton Court Palace, Richmond Park and Bushy Park. Richmond also has 21 miles of river front and is the only borough where residents live on both sides of the river.

Richmond has a population of 195,200 people. By 2029, the borough's population will rise to 213,582 with the largest increase seen within the 80+ year old residents. Approximately 16% of the population of Richmond are over 65 years of age compared to 12% in London and 18.5% nationally. The proportion of Richmond's population in all age groups above 40 is substantially higher than the London average.

Life expectancy is high and rates of premature mortality are lower than other areas. Richmond residents are living longer than ever before but in recent years the rate of increase in life expectancy has decreased both locally and in England.

Richmond is one of the six boroughs in South West London and part of the South West London Integrated Care System (ICS), formerly the South West London Clinical Commissioning Group (CCG).



## 1.3 Describing the dementia system

Dementia covers many areas of health and social need. A multidisciplinary and systems thinking approach helps bring together and coordinates the full range of interventions required to meet residents needs.

At a local level strategic dementia prevention and care activity of the refreshed 20-22 Richmond joint dementia strategy was overseen by Richmond Dementia Pathway Leadership Group (DPLG). The DPLG brings together colleagues from the ICS, Council and voluntary sector.

NHS systems have consolidated at the regional level, which for Richmond is Southwest London. The Southwest London Integrated Care Board (ICB) brings together efforts to improve population health and care across the South West London footprint. The ICB is developing a mental health strategy for the region. dementia is one of its work-streams .

### London

The London Dementia Clinical Network aims to provide 'leadership and advice to shape London's dementia services so that people with dementia receive an effective diagnosis, treatment and care. They focus on quality improvement, transformational change at a London whole system level while the ICB is responsible for commissioning.

They spearheaded activity across London to improve dementia diagnosis rates.

### South West London

The NHS South West London Integrated Care Board is a statutory organisation bringing together the NHS to improve population health and establish shared priorities for local people. They are a partner in the South West London Integrated Care System which brings the NHS, local councils and community together to plan and deliver joined up health and care services. They are developing a new mental health strategy for South West London. Dementia is one of the workstreams.

### Richmond Dementia Pathway Leadership Group

The Richmond Dementia Pathway Leadership Group (DPLG) is a multi-agency group with membership of dementia health and social care stakeholders. It oversees the strategic approach to dementia prevention and care activity in Richmond and led on the implementation of the Richmond joint dementia Strategy.

Colleagues cited it as a great platform to bring colleagues from the Integrated Care System (ICS), Council and voluntary sector together. It was cited by the Alzheimer's Society member as 'evidence of a good and knowledgeable approach to dementia across the system'.

Specific key actions led by the DPLG to date include data collection of the number of people with dementia from a protected characteristic within the Community Independent Living Service (CILS) contract, an developed an Equality statement, and a dementia prevention and hosted a care showcase event held in February 2022.



## 1.4 Assessing need

Dementia strategy is underpinned by the 2019 Richmond Dementia Health Needs Assessment and intelligence from the 2021 [Joint Strategic Needs Assessment](#)

- In 2020, there were 1,412 people aged over 65 in Richmond who had a recorded diagnosis of dementia. At 4% this is a lower prevalence than the London average and similar to the England average (4.2%). The borough ranked 15th lowest in London.
- Based on 2022 dementia prevalence estimates, 66.9% of dementia patients in the borough have received a diagnosis of dementia. The diagnosis rate is similar to the London average of 66.8% and higher than the England average of 62.0%.

### Strategic Needs Assessment JSNA

- In 2019-20 there were 1,065 emergency hospital admissions for people with a mention of dementia (3,254 admissions per 100,000 of the population aged over 65). This presents a 12.8% decrease from previous year. The borough rate was significantly lower than the London and England rates.
- The rate of mortality in people aged over 65 with a mention of dementia in 2019 was 680 deaths per 100,000 of the population in Richmond (227 in total). This figure shows a 10.9% increase from previous year. The borough's rate was lower than London rate (722 deaths per 100,000 of the population) and significantly lower than the England average of 849 deaths per 100,000 of the population. Richmond is ranked 10th lowest across London.
- 10 of the 15 CIPFA nearest neighbours to Richmond have higher recorded prevalence of dementia than Richmond. A higher proportion of Richmond's population are living with a diagnosis of dementia (0.6%) than average in the rest of London (0.5%). This is, in part, due to the high proportion of people aged ≥65yrs in the borough (15.4%) - [Dementia Health Needs Assessment 2019](#).

### Young Onset Dementia (YOD)

Dementia is considered 'young onset' when it affects people under 65 years of age. It is also referred to as 'early onset' or 'working age' dementia. People with dementia whose symptoms started before they were 65 are often described as 'younger people with dementia' or as having young-onset dementia.

- People aged under 65 years account for 3.3% of dementia cases in Richmond.
- The number of people in Richmond with a Diagnosis of YOD is around 50, however only 35 are accounted for on a GP register..
- It is estimated there are 327 people with YOD across South West London. People with YOD felt that its socio-economic impact is not understood by either health or social care.
- At the time of diagnosis, people are usually in full time employment, managing mortgages and can have dependent children home.

The impact of having a young onset dementia diagnosis is very different to developing dementia at an older age. Research is showing footballers and rugby players are particularly vulnerable to YOD. The Young Dementia Network is a movement of people committed to improving the lives of those affected by young onset dementia.

The symptoms of dementia are not determined by a person's age, but younger people often have different needs and require different levels of support and interventions.

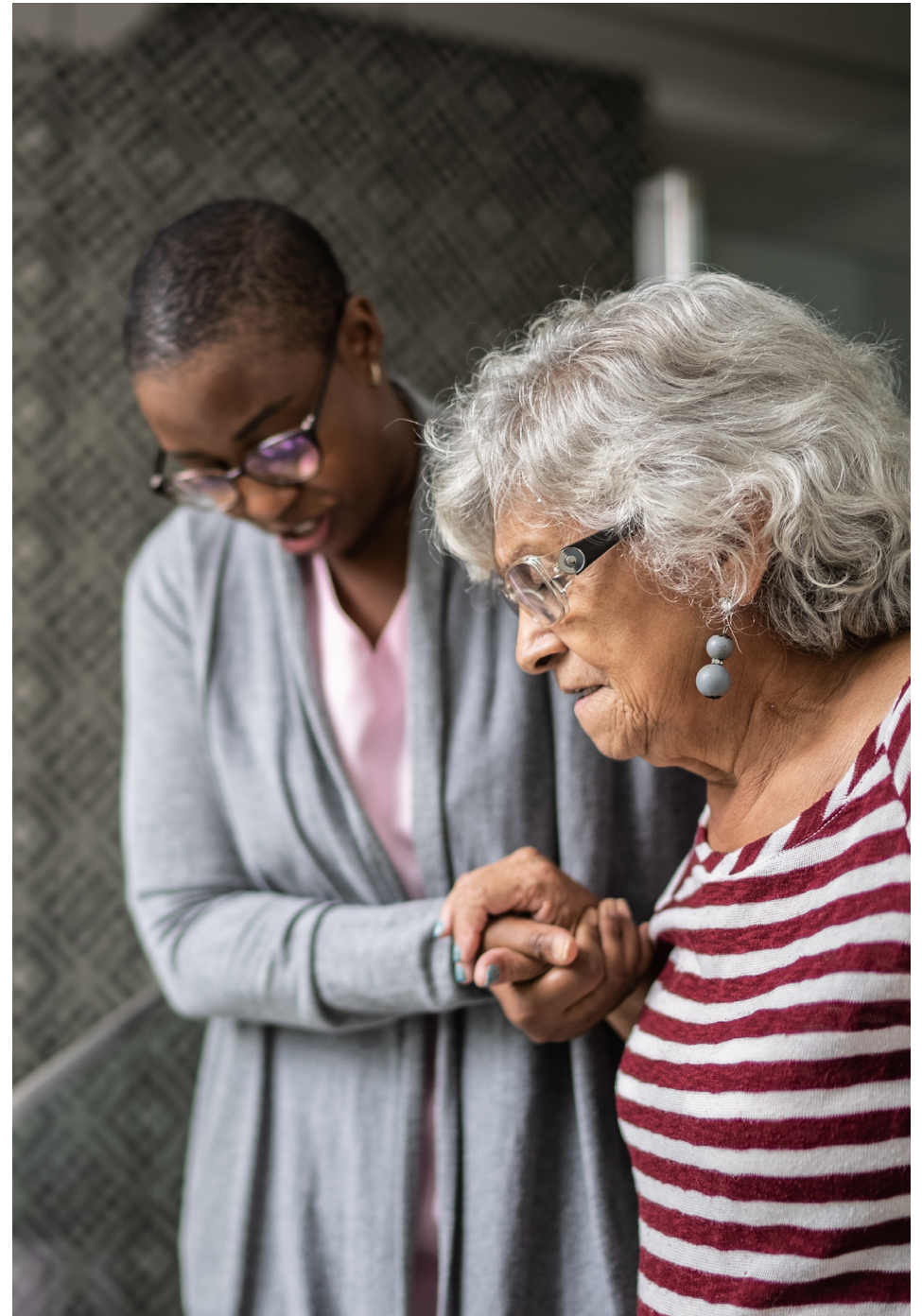
Engagement work was carried out across south west London by the Health Innovation Network (HIN) on behalf of South London Mental Health and Community Partnership (SLP) working group. The focus was on Young Onset Dementia during October to November 2019. The engagement team met with young persons with dementia and their carers to understand their current lived experience of having a YOD diagnosis and the support they receive.

## Research findings

- There is a need to offer psychological support to the children of young people with dementia and adult family carers.
- Access to speech therapy is a highly valued, but scarce resource.
- The financial and employment impact on families of working age is a source of great concern, providing access to financial advice and employment support should be prioritised.
- Clear communication pathways need to be set up between hospitals, GPs and support services (e.g. Alzheimer's Society).
- Support services that are integral to the diagnosis process are highly valued.
- GPs should receive more guidance on 'signs and symptoms' of young onset dementia through the patient presentation/families' stories (recognising the complexity of diagnosis of this disease).
- People with young onset dementia, their children and carers are isolated. Consideration should be given to a digital response that enables peer to peer support 24/7.

## Specific issues for YOD carers

- Pressure to give up work to care for YOD loved ones therefore professional loss, income loss etc compounds that of the whole family.
- If a person with dementia's sleep is disturbed it affects carer's ability to function.
- These carers are often looking after grandchildren or their own children as well as elderly parents, so life becomes very challenging, they risk dropping out of any social life which does not involve family duties.



## Feedback from people living with YOD in Richmond

- GPs lack understanding of YOD as well as dementia generally.
- There is a lack of age appropriate respite; these clients do not want to be with older cohorts of people with dementia as they have little in common and their needs are different.
- There is a lack of age appropriate activities, they do not want 'sing along' sessions or crafts, but to be doing exercise, cultural or intellectual activities or voluntary work.
- They have financial worries for their family's future including dependant children and aging parents.
- There is reluctance to spend money on their own care needs because of worry about the family's future and do not want to deprive them.
- There is a lack of transport support when they are unable to drive, and existing disability community transport is not wanted by YOD client due to stigma or they do not have mobility problems or do not want to see their possible future with higher needs service users.
- They can be forced out of work prematurely and suffer financial penalties and income worries.
- There is a lack of purpose in life; it is hard to adapt to empty days especially if a spouse is working.

## Support for the YOD population in Richmond.

This population need age appropriate support:

- Alzheimer's Society provides group support for this group. The focus will be around case finding going forward and signposting to YOD initiative.
- Alzheimer's model of providing more 1:1 support and moving away from group work has been welcomed.
- YOD Peer navigator with a focus on developing pathways to access services.

## Audit Of Referrals To Richmond Community Mental Health Team Older People 2019

- Review of all referrals received by the Richmond CMHT OP over a 4 week period.
- Increasing number of referrals to the team, with the highest in CMHA service line, despite other boroughs having higher 65+ populations.
- The majority of referrals were from GPs.
- 85% of the overall input provided by Memory Assessment Service (MAS) is dementia related.
- Highlighted improvements that could be made to improve the referral information referrals to include blood dementia screening, details of main carer/Next of Kin (NOK) NOK and information about other agencies involved.
- The audit concluded that Integration or co-location of a social worker in Richmond CMHT-Older People is needed to reduce delays and improve coordinated approach/ reduce risk of complications and crisis in people affected by dementia.
- Need for more robust post-diagnostic pathway, including information dissemination, coordination of services, gaps in evidence-based therapeutic interventions e.g. Cognitive Stimulation Therapy.

**"The impact of having a young onset dementia diagnosis is very different to developing dementia at an older age."**

## Adults and older people's mental health needs assessment, 2022

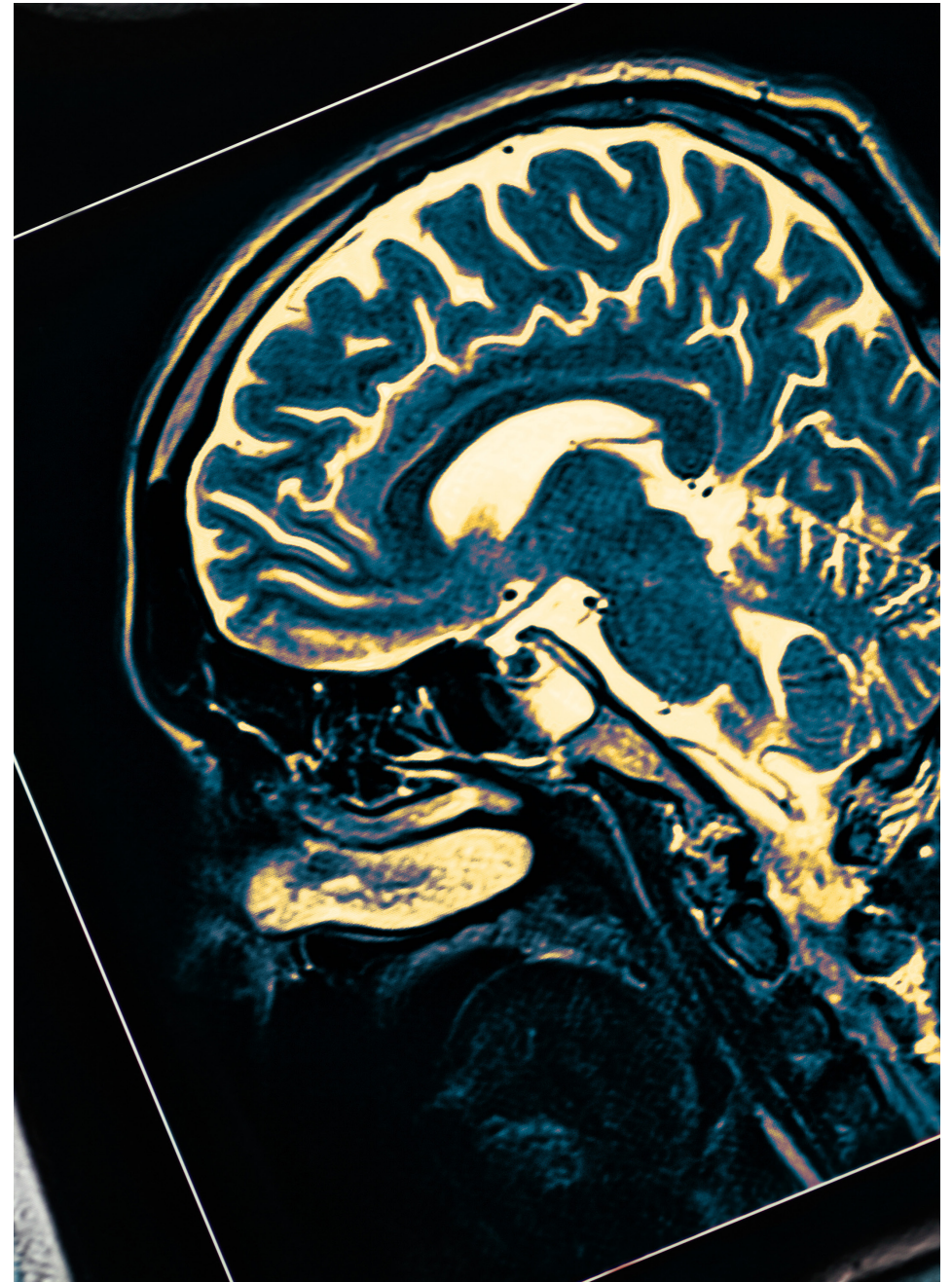
An Adults and older people mental health needs assessment carried out post pandemic found there is increasing complexity of mental health needs but a lack of services to manage them. The dementia related key findings were

- The system lacks an integrated approach to mental and physical health in older people.
- Significant barriers exist to accessing and receiving mental health services including long waiting lists, limited time and resources and the threshold for acceptance.
- Awareness and understanding of the pathway between local mental health services is limited.
- Older people experience high levels of isolation and face barriers to accessing mental health services. This is due in part to increased digital delivery.
- Services are not able to be flexible to meet individual needs.
- Richmond has a high number of people living with dementia due to the large population of older adults in the borough.
- There is significant pressure on voluntary and community sector groups who support the mental health of older people.
- Particularly vulnerable groups identified include service users with neurodiversity and/or learning disabilities, those with co-occurring mental health and substance misuse disorders, carers, homeless service users, those facing poverty and Black, Asian and minority ethnic groups.

The number of dementia care plans that have been reviewed is decreasing and lower than the London average.

### Recommendation from the needs assessment

One of the recommendations of the needs assessment was to improve access to psychosocial support for the family and carers of people with dementia including bereavement and talking therapy services.



# 1.5 Evidence underpinning the strategy

## National Research

As an evidence-based strategy, best practice and evidence from research has helped shape work across the dementia pathway and the development of this strategy. Some of the key research used in this strategy is outlined below.

### Diagnosis support and the impact of COVID-19

The *Left to Cope Alone The unmet support needs after a dementia diagnosis* report by Alzheimer's Society, (2022) highlighted that a diagnosis without sufficient post-diagnostic support leaves people living with a complex and potentially devastating condition with limited understanding, capability or tools to cope with or manage its symptoms.

In addition, another Alzheimer's Society report Worst hit: dementia during coronavirus report sets out the impact coronavirus had on everyone affected by dementia and those who care for them. The largest increase in excess non-COVID-19 deaths was in people with dementia. The report also recognised the high death rate in care homes, significant cognitive decline for people who live in the community and rising mental health challenges for unpaid carers. Alzheimer's Society called on the NHS and local authorities to set out how they will involve social care providers and care homes in future winter pressure planning

*Inclusive (social) citizenship and persons with dementia, Ruth Bartlett, University of Southampton (2022)*. This study on the Inclusive (social) citizenship and persons with dementia examined the outdoor experiences of 15 persons with dementia living at home in southern England, to find out what access means for someone with a neurological condition and showed how important it is to take account of cognition when promoting access rights for disabled people, including people with dementia. The study found that:

- Access to the outside world is important for disabled people, including people with dementia.
- Access work involves 'access to location technologies' 'access to ordinary places', and 'consciously sharing the responsibility of access work'.

## Modifiable risk factors

The dementia prevention, intervention, and care: 2020 report of the Lancet Commission outlined the importance on focusing on a life course for dementia prevention. In the same report, new evidence supports adding three new modifiable risk factors—excessive alcohol consumption, head injury, and air pollution—to the 2017 Lancet Commission on dementia prevention, intervention, and care life-course model of nine factors (less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, and infrequent social contact). The report highlighted that modifying 12 risk factors might prevent or delay up to 40% of dementias. The report identified specific actions for risk factors across the life course that can be taken and that all should be ambitious about dementia prevention in their plans.

## Identifying the need for increasing access to a dementia diagnosis in ethnic minority communities

The Alzheimer's Society have recently published three reports published in 2021, on dementia diagnosis, to identify and address the challenges faced by people accessing a dementia diagnosis. The reports make a series of recommendations aimed at Integrated Care Systems. The first report focuses on ethnic minority communities, identifying the need for increasing access to a dementia diagnosis by reducing community barriers to dementia diagnosis, improving identification and referral processes, making services more culturally appropriate, Improving access to, and quality of, interpretation services, and improving access to appropriate diagnostic tools as well as encouraging better demographic data collection.

## Regional variation in increasing access to a dementia diagnosis

Although not specific to Richmond, The second Alzheimer's Society report focuses on regional variation in increasing access to a dementia diagnosis, highlighting the need for increased dementia case-finding and improved identification processes. Improving and streamlining referral pathways will enable primary care to undertake more diagnoses, recognise mild cognitive impairment and monitor cases. It will also ensure people in rural communities can access a diagnosis, improve the quality of dementia coding and reporting and encourage better partnership working across all those involved in diagnosis.

## Increasing access to a dementia diagnosis in hospital and care homes

The third Alzheimer's Society report focused on hospitals and care homes, with recommendations to tackle the impact of delirium on dementia assessment highlighting the significant challenge to distinguish between delirium and dementia. Their recommendation to implement dementia and delirium pathways to ensure proper assessment of both conditions whilst in hospital. The report also identifies the need to ensure dementia assessment is prioritised upon admission, the need for improve staff skill and confidence, better access to information, implementation of a sufficient discharge planning process to reduce instances of lack of assessment post-discharge. In care homes, this report also identified the need for improved care home staff confidence in identifying dementia, the need for improved processes to increase identification of dementia in care home populations, enabling better access to clinical teams, improvement of use of assessment tools and access to information.

## Ethnicity and prevalence of dementia

A recent study by University College London and the London School of Hygiene and Tropical Medicine found that people of black and South Asian origin with dementia die younger and sooner after being diagnosed than white people.

It was the first study to investigate the incidence and prevalence of dementia, as well as age of diagnosis, survival and age of death, across white, black and South Asian ethnic groups using electronic records kept by GP surgery and hospital staff. Further investigation is needed to identify the reasons for this, e.g., whether dementia is picked up at a later stage in minority ethnic groups and therefore people decline faster, if underlying risk factors in these groups contribute to worse overall health or if there is a difference in post-diagnostic support that results in these differences.

## New practice from new research

There is new practice-based research being undertaken as part of the [ESRC-NIHR MODEM project](#) (modelling outcome and cost impacts of interventions for dementia). MODEM talk to 300 people and their carers who live with dementia, charting their lives over a whole year. MODEM are currently reviewing evidence on medications, cognitive stimulation and other therapies, exercise, nutrition, telecare, community initiatives, respite and training for carers. The outcome of this work in due course will be the creation of a public web-tool. This will allow commissioners, providers, advocacy groups, individuals and families to access the project's outputs, and make their own projections of expected care and support needs, outcomes and costs.

The Personal Social Services Research Unit (PSSR -Kent) and Care Policy & Evaluation Centre (London School of Economics) are also involved in ongoing research looking at measuring the social care outcomes of people with dementia and their carers which will be reviewed in due course as research is published.



## Local Research

### Pandemic impact and recovery

Social isolation has always been a significant risk factor for people living with dementia. This is perhaps more acutely felt in Richmond which has the highest proportion of people over 75 living alone in London (51% compared to 35%). The Alzheimer's Society reported that before the COVID-19 pandemic nearly two-thirds of people with dementia said they felt anxious or depressed, and of those living alone, nearly two-thirds report feeling lonely.

Local providers of support services for unpaid carers reported that residents who are looking after people with dementia, experienced more stress than usual during the pandemic. In part, this is because many of the services closed during national lockdowns, and thus unpaid carers needed to spend more time looking after their loved ones.

Services worked hard to ensure outreach or virtual services were available and deliver face to face support in line with government guidance and practice, operating in a pre- pandemic way. Continuing to develop communities that are dementia friendly will help strengthen the resiliency of unpaid carers.

### Richmond Dementia Report - Emerging learning and recommendations in the context of COVID-19

Richmond Public Health published a report in 2020 entitle Richmond Dementia Report - Emerging learning and recommendations in the context of COVID-19 across the local dementia prevention and care pathway. This report considered emerging local learning and made recommendations for improvements to meet the changing landscape across prevention, diagnosis, and care of dementia in the context of COVID-19.

The key recommendations include:

- South West London Clinical Commissioning Group, South West London and St George's Mental Health Trust and South West London Integrated Care System could consider reviewing current referral pathways both during and following the COVID-19 pandemic. The importance of facilitating Social Services attendance at MDT meetings will support this.
- Work is needed to encourage care homes to think differently about the potential to increase family interactions.
- Adult Social Care need to ensure all social work teams are fully aware of the range of services offered such as carers assessment as well as regular reassessment of care for patients within their home setting.
- There is a need for dementia champions across the Adult Social Care Directorate.
- The London Borough of Richmond upon Thames Council, South West London CCG and South West London and St George's Mental Health Trust should audit the proportion of frontline care professionals who have completed NICE recognized dementia training.
- Low-level psychosocial support for unpaid carers should be added to the current dementia pathway.
- There is a need to consider increasing availability and flexibility of respite care, including day care centres, and home care to facilitate unpaid carer wellbeing and reduce isolation.
- The Alzheimer's Society training for unpaid carers offer as part of the carers hub contract should be reviewed.
- There is a need for support to navigate the support system for all unpaid carers, regardless of funding status.
- It is important to better understand the current digital offer and what digital solutions could be implemented to improve this offer.

## Richmond Clinical Commissioning Group (CCG) research on what 'good' looks like

Work done by the Richmond Clinical Commissioning Group (CCG) asking what good dementia prevention and care looks like for people with dementia and their carers reveals.

### 'I was diagnosed in a timely way

- We know that if I am referred for an assessment for dementia, I will receive a timely diagnosis and agree on an initial care plan.

### 'I am able to make decisions and know what to do to help myself and who else can help me.'

- We know that I will have a personal choice in decisions affecting my care and support.
- We know that I will be able to jointly develop my care plan.
- We know that if I need help, I will be supported to make a decision e.g. through the use of independent advocacy services.

### 'I am treated with dignity and respect.'

- We know that services are designed around us and our needs, and that they will be appropriately staffed and staff will have the right levels of training.
- We know that services will provide the best possible care, and will be regularly reviewed by other agencies.

### 'I get treatment and support which are best for my dementia and my life.'

- Once I am diagnosed, we know that we will have a named coordinator of care who will jointly review my care plan with us as our needs change. This will happen at least once a year.

### 'I am confident my end of life wishes will be respected.'

### 'I can expect a good death.'

- We know that my care plan will help us to plan for the future, including my end of life wishes.

## Statements from other work include

"We want to be accepted by all in the community"

"Richmond is a Dementia friendly borough, where people living with Dementia and their unpaid carers feel accepted in the community"





## 1.6 Policy context

### National Dementia Strategy (due 2022)

Living well with dementia: a national dementia strategy was first published in February 2009, setting out a vision for transforming dementia services, with the aim of achieving better awareness of dementia, early diagnosis and high quality treatment at whatever stage of the illness and in whatever setting.

In 2015, The Government published the Prime Ministers Challenge on dementia 2020 which described the need to improve recognition and quality of care for people with dementia.

The Government now plan to publish a new stand-alone 10-year Dementia Strategy, focusing on how to improve the lived experience of people living with and affected by dementia. Ensuring the inclusivity of dementia goes beyond the remits of the health and social care system and The Department of Health and Social Care (DHSC) is continuing to engage with other government departments as part of the development of this new national 10-year dementia Strategy, which is expected in late 2022.

There are 4 main areas of focus: in the national strategy are

- Prevention.
- Personalisation.
- Performance- Systems working better.
- People- Patient Experience.

### People at the Heart of Care

The Government published the social care reform white paper in December 2021, People at the Heart of Care, which addresses the challenges that people experience when navigating the adult social care system, including those with dementia. It set out policies that are designed to improve information and advice.

The NHS Long Term Plan further commits to further improving the care for people with dementia, identifying dementia as an improvement priority.

### London Dementia Clinical Network

- Memory services spotlight audit
- Appropriate prescribing
- Audiology and memory tool- screening in audiology clinics and screening for hearing
- Prison – older people
- Awaiting publication

### Richmond Carers Strategy

Our vision for Carers in Richmond is that they are able to achieve their full potential, live their lives with confidence and resilience, and access circles of support and quality services that promote independence and deliver value for money.

Four key priorities have been developed based on local engagement with carers, a Richmond Carers Needs Assessment, and national strategic initiatives. These four priorities are:

**Priority One-** Improving the Recognition of Carers

**Priority Two-** Mitigating the Economic and Academic Impact of Caring

**Priority Three-** Creating Carer Friendly Services and Communities

**Priority Four-** Improving Carers Health and wellbeing

## **Hounslow & Richmond Community Healthcare (HRCH) - London Borough of Richmond Joint Strategy for Dementia 2022-2027**

Richmond's Joint Strategy for dementia was produced in 2017 and has been one of the major influencing factors in our own vision for dementia care. The Borough is now reviewing and updating this to produce a 10-year plan to commission an integrated dementia pathway.

HRCH provision needs to be reviewed in conjunction with the boroughs plans to ensure it integrates smoothly and effectively into the wider dementia pathway to support local objectives.

HRCH recognise that we are part of a network of providers in the borough and have been able to contribute to both the development of Richmond's Strategy as well as participate in multi-agency strategy, planning and delivery groups, including the Older People's Mental Health Forum, the Dementia Pathways Group and Kingston Hospital.

There has been a major drive to raise the profile of dementia and its causes as well as the need to identify dementia as early as possible and ensure the many agencies nationally and locally come together to co-ordinate care that enables people to live well regardless of their diagnosis. There have been and still are challenges about the stigma of dementia. There has also been a major focus on ensuring family carers are recognised and supported in the vital work they do in an unpaid capacity to help their loved ones, neighbours and friends to live well and to live as independently as possible at home.

Hospitals and inpatient settings have been encouraged to make their environments dementia friendly and communities have been working to create dementia friendly towns and villages.

There is a consensus that all professionals should be helping people living with dementia to live well and this is enshrined in the 'dementia Well Framework', which promotes best practice.

Best practice in dementia care demands that a comprehensive assessment of need is undertaken to provide an holistic and person centred approach and that unpaid and family carers are consider and treated as equals in the provision of care.

## **HRCH Eight principles (of effective service provision):**

- 1** Appropriately resourced
- 2** Partnership working
- 3** Evidence based
- 4** Prevention focused
- 5** Empowering
- 6** Prioritise what is possible/achievable.
- 7** Equality, Diversity and Inclusive
- 8** Access to universal services

# 2

## DEVELOPING THE STRATEGY

“A strategy would need to recognise that the nature of services provided for those directly requiring the services also impacts on and can support their friends and family if they are providing unpaid care.

A good example is day centres which typically provide predictable “space” for carers away from the potentially enclosed relationship with the person they support.

Essentially the type of support that a strategy aims to deliver would benefit from being explicit about what is proposed will benefit both people with dementia and those, if any, who provide unpaid care.”

Bruno, Richmond CVS

## 2.1 Strategic vision

The London Borough of Richmond upon Thames has invested significantly over the last few years in health and social care services in both the statutory and voluntary sectors for people with dementia and their carers. Overall, the policy context in Richmond describes a recognition of people with dementia and their carers, in addition to acknowledging the need for improved service accessibility in the borough.

The 2016-2021 dementia Strategy set out a five-year vision for people with dementia and their carers. It described five key strategic objectives to improve dementia prevention and care in the borough (preventing well, diagnosing well, living well, supporting well and dying well). The strategy aimed to capture the existing framework of comprehensive service provision in one place, demonstrate the choice and range of services available to people living with dementia and their carers, and highlighted where more work was needed. It also set out how health and social care services for people with dementia and their carers would develop over the next five years from 2016-2021.

In 2019, the council refreshed the borough’s dementia offer and planned initiatives for the remaining duration. This was to meet the growing need for a clear, consistent and co-ordinated offer of advice, support and targeted intervention from all agencies, working together). This would improve dementia awareness, access to equitably distributed dementia-related services and quality of local dementia-related services.

Building upon the successful completion of the previous strategy, a new ten year Joint dementia Health & Care strategy is now being put in place. This is a joint strategy and it combines the efforts of health and care and is delivered across an integrated care system

**The vision of the 10 year strategy is:**

For Richmond residents affected by dementia to live well throughout their lives with the right support and care.

## 2.2

# Aims, approach and principles

This 10-year Dementia Health and Care Strategy builds on the dementia pathway and what was learnt from delivery of the five dementia pathway priority phases.

### This strategy will:

- Promote prevention through raising awareness of the risk factors of dementia.
- Support people living with dementia and their carers to have the help they need to live healthier lives.
- Increase awareness of dementia within the community and of the support available to people with dementia and their carers.
- Ensure that the needs of unpaid carers are acknowledged and incorporated in any related strategy.
- Ensure that the support available enables people with dementia to live well at home for as long as possible.
- Ensure that the residents know where to access dementia information, advice and help, including a range of digital and non-digital tools to support people with routine tasks.
- Increase detection of dementia in GP practices and care homes, day centres and among people living alone.

### Principles which will underpin the strategy.

- Appropriately resourced
- Partnership working
- Evidence based
- Prevention focused
- Empowering
- Prioritise what is possible/achievable
- Equality, Diversity and Inclusion
- Access to universal services



## Equality, Diversity and Inclusion (EDI)

Ensuring equality, diversity and inclusion is important in working in a dementia prevention and care landscape. Over 2021 and 2022 the DPLG developed their EDI position statement. This is reflected in the actions and service of all DPLG members to reduce health inequalities and meet the needs highlighted in the EINA.

### The evidence shows that:

- LGBTQ+ individuals may not reach out for services and support because they fear poor treatment due to their LGBTQ+ identity, because they fear the stigma of being diagnosed with dementia, or both.
- While dementia disproportionately affects people over the age of 65 years, younger people may also develop dementia (young onset dementia) and face particular challenges related to their age, as well as their LGBTQ+ status.
- HIV, which disproportionately affects men and LGBTQ+ sex workers, a disproportionate amount of whom are trans women, has been linked to dementia. An untreated HIV diagnosis can lead to HIV-associated neurocognitive disorder (HAND), which can affect individuals of any age.
- People with learning disabilities have a higher risk of developing dementia than other people and usually develop the condition at a younger age.
- People with Down's Syndrome have a greater risk of developing dementia, one in three of whom will develop dementia in their fifties. Symptoms of dementia can present differently so that people often don't recognise changes as being dementia related. As a result of this, opportunities for early intervention are lost.
- South Asians seem to develop dementia – particularly vascular dementia – more often than white Europeans and have a higher risk of stroke, heart disease and diabetes, and this is thought to explain the higher dementia risk.
- Similarly, people of African or African-Caribbean origin seem to develop dementia more often. They are known to be more prone to diabetes and stroke.
- All of these effects are likely due to a mix of differences in diet, smoking, exercise and genes.

### LGBTQ+

Family of Choice is a term pre-dominantly used by the LGBTQ+ community. These are the individuals we wish to support us and want to be our voice when we are not able speak for ourselves. This might be a group of individuals who we consider to be our families, husbands, wives or close friends.



## Actions

There is work across the Council to ensure that the needs of unpaid carers including those supporting people from diverse communities are met. The Council held an event that focussed on LGBTQ+ and Asian Carers. The aim of this work is to provide health and social care staff with an increased understanding of unpaid carers issues and rights, and in particular the issues that LGBTQ+ carers face. A toolkit will help services to identify and explore ways of supporting LGBTQ+ carers and the barriers they face accessing support. It will include models of good practice and a commitment to being LGBTQ+ inclusive.

## Challenges identified in relation to protected characteristics and dementia

- Ensuring adequate identification of dementia among ethnic minorities
- Providing support for family members of people with dementia who may not be the primary carer.
- Understanding the carers perspective.
- Ensuring flexibility in the carers offer including use of local resources, direct payments and out of hours services.
- Understanding and recognising the impact of unconscious bias including the assumption of certain groups providing support within their own communities.
- Ensuring effective data collection to improve and provide a positive service offer.
- The need for the interdependence across the various services and provisions to be mapped to reduce duplication and effective resource management.
- Ensuring adequate planning around proactive support and contingency planning.

## Next steps

- Training for all staff and care providers to enhance the support provided.
- Working to ensure that the voice of unpaid carers are heard and their views are incorporated in how services are commissioned and provided.
- Creation of a cohort of local residents who can contribute to service redesign as a "Lived Experience", the need to ensure payment and carer relief.
- Role out appropriate and relevant training for all staff and care providers to enhance the support provided.
- Develop Richmond Dementia Champions across all teams and services so that the needs of individuals living with dementia and their unpaid carers are at the forefront of all contacts.



## 2.3 Dementia Pathway Priority Phases

### Richmond Dementia Prevention and Care priority phases

The Richmond Health and Care Dementia Strategy builds on the Dementia Prevention and Care Pathway and focuses on what was learnt from delivery of the five dementia pathway priority phases from prevention to end of life care to date.

Work done during the strategy development and consultation found that the dementia pathway five priority phases remained relevant and useful. Essentially they remain the same and have been refined based on the learning and comments.

The Dementia Prevention and Care Pathway consists of five priority phases:

**Priority phase 1** - Preventing and reducing risk of dementia

**Priority phase 2** - Diagnosing dementia well

**Priority phase 3** - Supporting after diagnosis

**Priority phase 4** - Enabling a fulfilling life with dementia

**Priority phase 5** - Ensuring dignity and comfort for those dying with dementia

Action under each phase will be explored in the following pages of the strategy.

Using the concept of “prevention” for dementia can be problematic. It is actually “reducing

risk. Having a healthy lifestyle can reduce the risk of vascular dementia - but may not prevent Alzheimer’s disease. It is important that people with Alzheimer’s should not be made to feel they didn’t do enough to “prevent” getting the condition.

### Points of focus

There are four points of focus under each priority phase within the dementia prevention and care pathway:

- Improving dementia awareness and Dementia Friendly Richmond
- Improving access to equitably distributed dementia-related services including an increase in community dementia practitioner team
- Ensure a smooth interface and navigation between services for people with social care needs arising from their dementia, informal carers and those who work with them
- Develop a digital approach that provides accessible and easy to use offers

# 2.4 Short, Medium and Long-term Strategic objectives

Dementia prevention and care pathway priority phase	Short- 2 years	Medium 2-5 years	Long 5-10 years
Carers	<p>To have increased awareness of the support available to people with dementia and their carers.</p> <p>To ensure that all people living with dementia and their carers have access to universal healthy lifestyle services.</p>	Richmond is a dementia friendly borough, where people living with dementia and their unpaid carers feel accepted in the community.	
<b>Priority phase 1</b> Preventing dementia and reducing risk	<p>To audit the dementia training available, identify what it covers, and ensure it meets identified need in Richmond.</p> <p>To strengthen system wide dementia awareness training, with an emphasis on improving understanding in areas where knowledge was found to be lower, in particular, risk reduction messages. Changes in knowledge and awareness among the SSA and public will be measured over time.</p> <p>To have increased awareness of dementia within the community and to ensure the consultation of people living with dementia is an ongoing process.</p>	To have all council owned and commissioned leisure centres dementia friendly in the first five years..	Continued awareness and training that reflects new research.
<b>Priority phase 2 -</b> Diagnosing dementia well	<p>For all Richmond GP practices to achieve the national dementia target for earlier diagnosis-NHSE 6-week referral to assessment target.</p> <p>To reduce the gap between those diagnosed with dementia and people who are not diagnosed but living with dementia.</p>		
<b>Priority phase 3 -</b> Supporting after diagnosis	For all Richmond residents with a dementia diagnosis to have co-produced Urgent Care Plan within a year of their diagnosis.		
<b>Priority phase 4 -</b> Enabling a fulfilling life with dementia	<p>Resident can access their support and care in a seamless manner.</p> <p>To have increased diagnosis of people living with dementia in care homes who are undiagnosed.</p> <p>To increase the number of community dementia clinicians and practitioner team by two whole time equivalent staff.</p>	<p>LBRuT to have all services the Council provides, or funds sign up to be members of DFR and commit to completing two action points annually.</p> <p>To have a range of digital and non-digital tools to support people with routine daily tasks.</p> <p>To have overseen a smooth transition from hospital care to health and social care.</p>	
<b>Priority phase 5 -</b> Ensuring dignity and comfort for those dying with dementia	To contribute to SWL End of Life Care strategy.		To be a leading dementia friendly borough, with more people with dementia remaining out of hospital and dying at home or in their usual place of residence with dignity.
Cross cutting	<p>To upskill voluntary organisations, volunteers, community health champions and other community partners and have meaningful contact.</p> <p>To establish the consultation of people living with dementia as an ongoing process..</p>	<p>To have incorporated key strands from the national dementia strategy.</p> <p>To have scoped a Dementia Hub and have clear co-produced plans in place.</p>	To have a decreasing trend in the incidence of vascular dementia in Richmond.



## 2.5

# Co-production and Engagement processes

### Co-production and the Care Act

The Care Act 2014 was one of the first pieces of UK legislation to include the concept of co-production in its statutory guidance. Co-production is an often-used term to describe partnership working between people who draw on care and support, carers and citizens to improve public services, alongside those that provide those services. Co-production is about sharing power and responsibility to develop strength-based services and includes elements of co-design, such as planning of services, co-decision making in the allocation of resources, co-delivery of services, and co-evaluation.

### Co-production in Richmond

A broad range of partners, commissioners, service providers, the voluntary sector, and the public have been involved in the development of this strategy. The strategy vision, objectives, and approach was developed and shaped through meaningful co-production and feedback on the priority phases and dementia hub opportunities. Engagement opportunities were scoped and incorporated for further consultation, so that local people and communities helped shape and influence the delivery of dementia prevention, care and support.

Engagement sessions with people with dementia and their carers took place in 2019, and the findings continue to inform actions taken by local health and care organisations to improve the wellbeing of people affected by dementia, including the wellbeing of people who care for those affected by dementia. The need for more carers support, and maintaining a key focus on awareness raising and training was identified as part of the Dementia Strategy refresh for 2020-2022.

Initially the strategy was planned as a 5-year strategy. However, following consultation and latest policy developments a 10-year strategy was suggested to improve outcomes for people living with dementia. There was agreement that there is a need to strengthen already existing services, with a blended approach to a more traditional dementia-friendly 'under one roof' hub. Further work will be done to implement a hub with a clear focus on the intended outcomes for people affected with dementia and their carers.

### Work with Communities

The Richmond Older People's Mental Health Group considered whether the original five priority phases of the dementia prevention and care pathway were still relevant, considered what health and care integration look like for dementia prevention and care, and how can this be reflected in the strategy and action plans, alongside considering what definition of a dementia hub should be used in the new strategy and what it should look like.

The dementia hub, five priority phases, aims and objectives was considered and discussed at Council-led co-production meetings, attended by people who have current or past experience of supporting someone with dementia, and led by the Community Involvement Manager at Richmond Council for Voluntary Service.

In addition, further co-production took place at a Positive Care Conference in September 2022. These sessions provided an opportunity for the iterative process and comments that were fed back into the development of the structure of the strategy. Through this consultation process, and an Equality Impact Needs Assessment, five strategic priorities were identified to remain relevant to drive forward the strategy.

Richmond Community Champions also contributed to the strategy development, by being involved in discussions on the five priority phases, aims and objectives and comments on delivery of the strategy.

The Richmond Carers Reference Group focused discussions on the five priority phases, aims and objectives and how this will help deliver the pathway, and considered delivery to ensure that carers needs were considered in the strategy.

## 2.6 Governance and Monitoring

The Joint Dementia Health and Care Strategy accountability is to the Richmond Health and Wellbeing Board and will provide annual progress reports. Consideration will be given to embedding more quality improvement targets as part of the action plans and delivering the strategic objectives set out in the pathway priority phase.

There will be defined and measurable actions to facilitate progress. Once the action plan is ratified, the DPLG will oversee the achievement of the agreed action points, using task-and-finish and pre-existing groups (e.g. Richmond Older People's Mental Health Strategy Group) where appropriate. This ongoing oversight function will also act to reduce the risk of siloed dementia work and increase reflexivity in an evolving health and care landscape.

Each partner organisation will be responsible for the delivery of its action plan and achieving the objectives of the strategy. Partners will develop a strategy implementation plan and the 2-year strategic objectives will be turned into an action plan. It is planned that this will be shared with the Health and well being board in 6 months

Oversight of the actions will also be carried out by Richmond Place Based Partnership; and the implementation of the plan will be monitored on a quarterly basis.



# 3

## THE DEMENTIA PREVENTION AND CARE PATHWAY

'We can grow old and wise while still keeping our brain healthy and our spirit young!'

Maria

### 3.1

## PATHWAY PHASE ONE

### Preventing dementia and Reducing the risk

#### 3.1.1

#### What do we mean by prevention and reducing risk?

The drivers for increasing dementia can be divided into of modifiable and non-modifiable dementia risk factors. Age, genetics, ethnicity and sex are non-modifiable. There are some things we can do throughout life to help reduce the risk of developing dementia.

A risk factor is something that increases your likelihood of developing a condition. The earlier in life that healthy changes are made, the greater the likelihood of reducing the risk of dementia, disability, and frailty.

There is strong evidence that suggests that a healthy diet, having adequate physical activity, controlling type 2 diabetes, controlling high blood pressure, stopping smoking, reducing alcohol consumption and being socially active may help to reduce someone's risk of developing dementia.

Modifiable risk factors need to be addressed before the onset of disease. In some instances, up to 30% of the most common forms of dementia may be amenable to prevention. Even after a diagnosis of dementia uptake of healthy behaviours can slow disease progression, this will improve quality of life as well as reduce the cost of dementia care.

Only about a third of UK adults think it is possible to reduce their risk of dementia, so we can all learn about positive lifestyle steps we can take to keep our brains healthy, and which may reduce our risk of developing dementia later in life. Our objective is to continue to raise public awareness around dementia and the actions people can take to reduce their risk of developing dementia.

The Lancet Commission on the '[Prevention and management of dementia: a priority for public health](#)' published in July 2017, identifies risk factors that, if eliminated, might prevent more than a third of cases of dementia. They noted a link between hearing loss and the risk of developing dementia. Work is underway to understand more about this relationship and whether wearing hearing aids can reduce risk in people with hearing loss.

[A report by the World Health Organization \(WHO\)](#) has also highlighted that engaging in the arts may help reduce the risk of cognitive decline.

The evidence for airborne environmental risk factors for dementia is starting to develop and there is some moderate evidence for air pollution exposures being related to dementia risk, particularly nitrogen oxides, particulate matter, and ozone.

### 3.1.2 Evidence underpinning the strategy

Dementia Awareness and Prevention will be prioritised so that the future population of Richmond upon Thames can tackle dementia more efficiently. Dementia is now the leading cause of death in England and Wales. The number of people living with the illness is increasing. It is estimated that by 2035 the number of people aged 65+ diagnosed with dementia will increase by 74% in Richmond.

#### Prevention and physical health

More than one third of cases of dementia are potentially avoidable through modifiable lifestyle factors. Changes in mid-life can have a significant impact on reducing risk. Regular exercise, mental stimulation, and maintaining a healthy weight can all help to prevent us from developing dementia or slow its onset. Smoking and drinking too much can increase our chances of developing the condition, with smokers 50% more likely to develop dementia than non-smokers. Similarly, those with Type 2 diabetes, high blood pressure in middle age or who are obese are at greater risk of developing the condition.

Overall, up to 30% of cases of the most common forms of dementia could be prevented. There are modifiable and non-modifiable risk factors for dementia. Age, genetics, ethnicity and sex are considered to be non-modifiable risk factors.

Modifiable risk factors, such as smoking and physical inactivity, need to be addressed, before the onset of disease, to prevent or delay dementia. It is thought that approximately 9.3% of cases of dementia in Richmond are attributable to physical inactivity and 4.9% are attributable to smoking.

Even after the onset of dementia, uptake of healthy behaviours can act to slow disease progression and improve quality of life, as well as reducing the cost of dementia care. NICE guideline 16, 'dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset', provides recommendations to delay the onset of dementia, disability and frailty and to increase the amount of time that people can be independent, healthy and active in later life.

Advice should be given about how to prevent dementia through everyday activities. This awareness should start right from school age and via local communities. The information could be distributed digitally and also through community workers. Prevention is better than cure and this is true for dementia more so than in other disorders.

Whilst it is not possible to influence the most significant risk factor of age, other measures are possible. Management of cardiovascular risk factors (such as diabetes, obesity, smoking, and hypertension) and participation in regular physical activity, can reduce the risk of cognitive decline and may reduce the risk of dementia.

Research shows that awareness of the risks of dementia amongst those who attend an NHS Health Check is higher than those who do not.

#### Prevention and mental health

Recent research into mental health and ageing suggests that building mental resilience and effective ways of tackling adversity is key to ensuring good mental health in older age. Early intervention on the impact of physical conditions on mental health and recognizing those for whom mental health challenges exist could better support people as they age. In addition, studies suggest that early detection and interventions for frailty could translate into prevention or delayed onset of dementia. Green spaces and physical activity.

There is good evidence of the benefits of spending time in the natural environment for people with dementia and their carers.

#### Early intervention

Key interventions aimed at influencing and reducing cardiovascular risk, improving physical and mental health, addressing social isolation and loneliness and combating drug and alcohol abuse are important avenues in dementia prevention. The Blackfriars consensus published in 2014 acknowledged that sufficient evidence exists, with which people can be empowered to reduce their risk of dementia through reduction of cardiovascular disease risk and improving brain health. In addition, there is evidence that stimulating cognitive functions throughout the life cycle is associated with a reduced risk of dementia. Cognitive Stimulation Therapy (CST) is a brief treatment for people with mild to moderate dementia which involves taking part in group activities and exercises designed to improve memory and problem-solving skills.

## Earlier awareness

GP surgeries should display the signs of dementia so that patients and family can look out for these. They should also provide information on who to contact and where to go for further advice.

## Dementia Friendly Communities

A dementia-friendly community is a city, town or village where people with dementia are understood, respected and supported. In a dementia-friendly community people will be aware of and understand dementia, so that people with dementia can continue to live in the way they want to and in the community they choose.

## Dementia Training Standards Framework

Consultation identified that the dementia Training Standards Framework (DST) commissioned by the Department of Health and developed in collaboration by Skills for Health and Health Education England in partnership with Skills for Care. It was developed to set out the training needed for staff in health and social care across three groups: all staff (Tier 1), staff directly supporting people with dementia (Tier 2), and staff in leadership roles (Tier 3). Tier 2 of the Framework includes person-centred dementia care, communication, health and wellbeing, families, and carers as partners in care, and more. Tier 1 covers only a basic level of awareness of dementia and is not sufficient for staff directly supporting people with dementia. Therefore it is beneficial that staff directly supporting people with dementia should be trained to Tier 2 of the Framework.

Alzheimer's Society recognise that some organisations may already have some alternate form of dementia training in place, in which case they recommend measuring current training outcomes against the Dementia Training Standards framework.

## Benefits of spending time in the natural environment

A Public Health England review highlighted how the wider determinants of health linked to the natural environment are fundamental pillars to improving health and well being and outlined the links between greenspace and health and wellbeing and concluding that:

- improving access to greenspace promotes healthy behaviours, such as engaging in physical activity and other recreation.
- greenspace also can improve social contacts and give people a sense of familiarity and belonging—cleaner, greener communities are places where people wish to live and work.
- they can promote social contact and connectivity, foster a sense of belonging, reduce isolation and loneliness and encourage a connection to nature.

Research also shows that there are benefits of spending time in the natural environment for people with dementia and their carers.

### 3.1.3

## What we have achieved since the last strategy

### DPLG subgroup Preventing dementia subgroup

- The London Borough of Richmond upon Thames and Richmond CCG Joint Dementia Strategy 2016-2021, was refreshed and presented to the Adult Social Services, Health and Housing Services Committee in 2020. Specific key actions led by DPLG to date are data collection of the number of people with dementia from a protected characteristic within the Community Independent Living Service (CILS) contract, an Equality statement.
- The refresh outlined the borough's dementia offer and planned initiatives until 2022, overseen by the Richmond Dementia Prevention and Care Pathway Leadership Group (DPLG).

The work of priority phase 1 is led by Public Health and Adult Social Care Commissioners.

## **Dementia awareness training**

- Ten dementia awareness training workshops have been delivered with a total of 151 attendees. Post training evaluation found that 91% of attendees stated their knowledge base was increased, and that participants felt encouraged to sign-up and become a Dementia Friend.
- Dementia information and awareness raising was a feature at the 'Full of Life' fair 2022 and at the Dementia Prevention and Care Showcase event in February 2022, which also included a session on how to become a 'dementia friend'.
- Public Health's Making Every Contact Count (MECC) initiative produced a new dementia care and support related module in 2021-22 entitled 'Recognising and Supporting People Providing Unpaid Care' in addition to the existing Dementia Awareness MECC module. The module describes what unpaid care looks like, considers the signs that suggest that someone is struggling with their caring role and explores how this might affect their overall health and wellbeing. This module was accessed and completed by 35 people, with 23 people having completed the dementia MECC module in 2021-22.

## **Dementia Awareness Survey**

- A dementia Awareness Survey (DAM1) was carried out across the whole of the Shared Staffing Arrangement (SSA) of Richmond and Wandsworth Councils to better understand the level of dementia awareness among SSA staff. A total of 326 SSA staff completed the DAM1 survey. Findings will inform the strategic approach to dementia raising awareness in health and social care staff.

## **NHS Health Checks Awareness Campaign**

- A marketing campaign to promote the NHS Health Checks programme to residents was developed with visual assets, including animation and film footage have been produced and were used to run highly targeted programmatic advertising in Richmond. Printed materials were strategically placed in targeted community settings.

## **Dementia Friendly Richmond**

- Dementia Friendly Richmond is the local dementia Friendly Communities initiative. dementia Friendly Richmond (DFR) is funded by Richmond Council and was re-launched in Spring 2021 with an objective to develop communities that are dementia friendly to help strengthen the resiliency of unpaid carers. It is delivered by Age UK Richmond (AUKR).
- The Dementia Friendly Richmond (DFR) contract has now completed its first 18 months. Local organisations and businesses each commit to 2 action points that contribute to capability building and improving the experience of those with dementia and their unpaid carers.

### **Achievements of the DFR initiative so far include:**

- Sign up from 62 local organisations, with all of them having submitted their action plans and almost 100 actions have been achieved since April 2021.
- Regular DFR network meetings are in place and the DFR co-ordinator continues to arrange regular learning sessions, for example, producing a video for the Police providing an overview of dementia.
- There are over 136 dementia Friends now in place across the Dementia Friendly Richmond Network.
- The DFR coordinator is now a member of Richmond Chamber of Commerce which will enable them to meet face-to-face with local businesses and encourage more businesses to join to make Richmond more dementia friendly.
- In the 2022 Dementia Action Week, a Dementia Information Day was held at Elleray Hall (a member of DFR) and attended by 70 people. There was a combination of talks and stands providing information about various aspects of the dementia journey.
- DFR members worked with the DF/ R co-ordinator to design an activities leaflet for Social Prescribers who reported that they struggled to get people living with dementia to attend activities. This is now shared with clients in the borough to benefit from support.
- Strawberry Hill House hosted training on Interacting Well with People with dementia, which was attended by 12 members of staff and volunteers. This was also delivered to Hampton Court Palace to 40 members of staff and to 8 members of staff at AUKR. The session looks at different types of dementia, symptoms and how we support people with dementia, acknowledging the challenges they face and the emotions and behaviours this can create.

## Friendly Parks for All

Since 2017 the parks team have run a series of monthly activities for people with dementia and their carers. The current programme is are listed on the council website and carried in the information sheets by the Alzheimer's Society.

There is a monthly Accessible Walk and 2 monthly dementia inclusive litter picks in Barnes Green and Kneller Gardens, Twickenham. All activities include an opportunity to socialise as well as spending time in beautiful parks getting exercise

Other opportunities in parks/open spaces run by other organisation in parks. People with dementia attend conservation activities e.g. Grow Wild in Richmond Parks, Richmond Green Gym and some of the Friends of parks groups meetings, walks and talks run by different organisations or make visits to the very many parks in the borough.

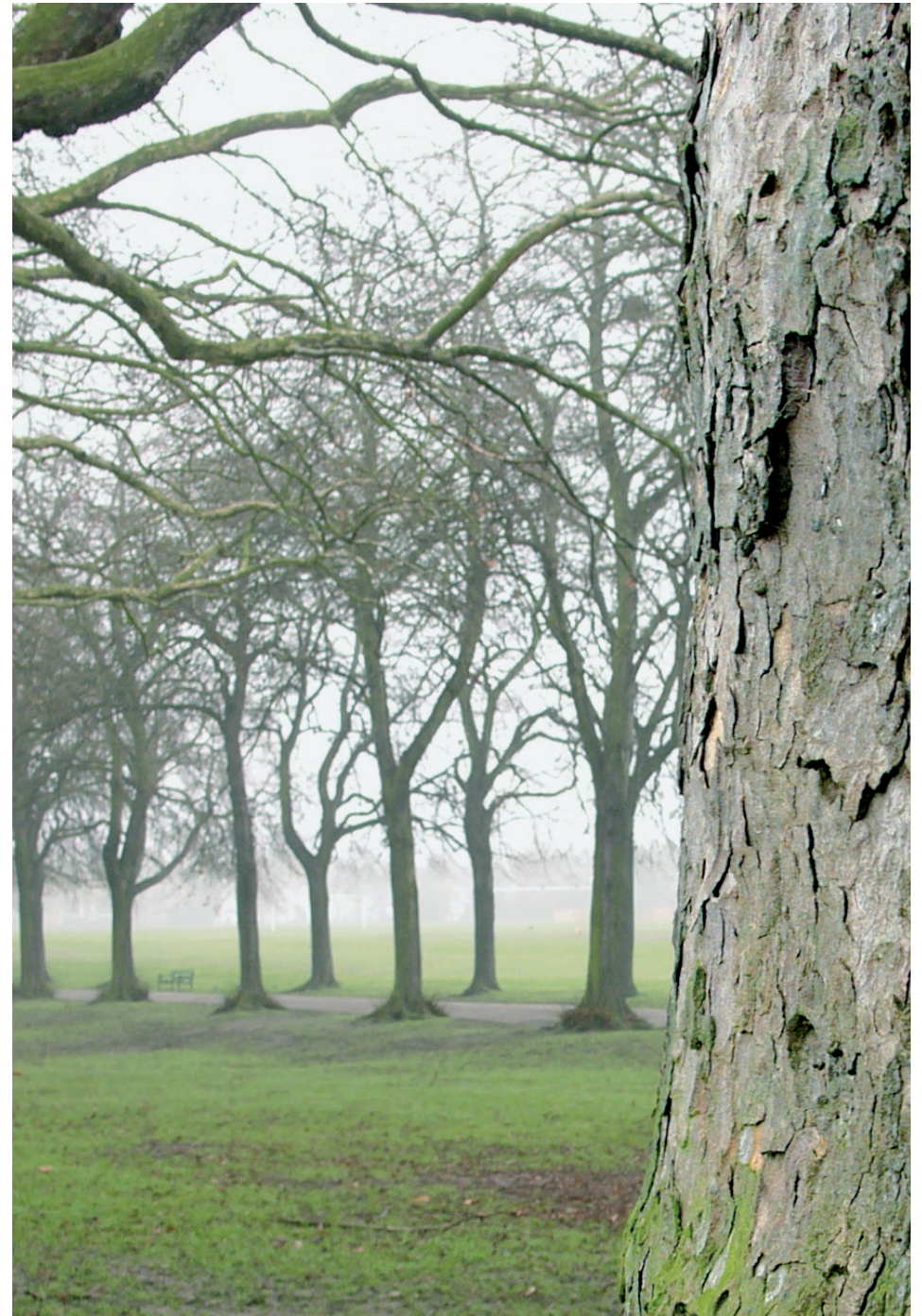
Let's Go Outside and Learn/Embracing Age intergenerational gardening project in 3 care homes in the borough.

[All Friendly Parks have access guides available on the council website:](#)

## Dementia Awareness Campaign- Think Brain Health' campaign

■ Public health have run campaigns using the "Cares for a healthier borough branding", delivering the 'Think Brain Health' and other national campaigns, and included increased access to physical activity in the Public Health Adult Physical Activity Plan, as well as building on existing physical activity opportunities and assets such as the Friendly Parks for All Project."

■ There are also plans to deliver a series of informal conversations amongst residents and community groups to increase awareness on risk reduction messages.



### 3.1.4 Pathway mapping

#### Preventing Well and Dementia Awareness

##### Prevention

Dementia assessment and screening to be included in GP yearly health check for over 65s.  
Consider a behavioural change if the following behaviours are present (smoking, excessive use of alcohol, lack of exercise, obesity, isolation, unhealthy food choices and poor sleep hygiene). Offer consultation with the practice nurse or dietician.

##### Public Health Information

Making healthy lifestyle choices may reduce the risk of dementia. Public health messages should link dementia risk to lifestyle factors, including smoking, excessive drinking, high blood pressure, lack of physical activities and diabetes.  
Include dementia in local campaigns on other issues such as cardiovascular disease, diabetes which are likely comorbidities.  
Reduce the stigma around seeking a diagnosis with messages that dementia is a disease of the brain and that treatments (not cures) may be available.  
Kingston and Richmond Communications and Engagement Group could be a route to supporting this.

##### Richmond interventions

'Reducing your risk of dementia' booklet to be made available in public places, libraries, council offices.  
Smoking cessation advice accessible to all via StopSmokingteam@richmond.gov.uk  
Access to IAPT for older people to reduce the risk of depression.  
Exercise on prescription e.g. Get Active, WW, exercise classes (to be commissioned).

##### Supporting Research

Encourage public to help prevent dementia by participating in [clinical trials and studies](#).

##### Dementia Awareness

**Dementia training and awareness sessions should be available to all sectors including:**

- GPs and community pharmacies, who play a role in screening for risk and advising on managing risk.
- Other primary care providers including occupational therapists, opticians, audiology, dentistry to appropriately signpost or support people.
- Adult Social Care teams so that they are empowered to provide person centered care.
- London Borough of Richmond upon Thames Council staff including at libraries and leisure centers to facilitate inclusive universal services.
- Voluntary organisations which offer form filling, personal assistant, shopping or befriending services.

**HRCH – Dementia Support Service** is available for advice on best practice.

**Alzheimer's Society** for information and advice about best practice dementia inclusive practices in the workplace and community.

**Age UK's Dementia Friendly Communities Richmond** aims to create an inclusive borough where people affected by dementia feel supported, included and understood in community life, to travel freely, receive appropriate care and support and feel confident to participate in cultural amenities and visit local high streets and town centres.

**Dementia Awareness Training** – The London Borough of Richmond upon Thames Public Health division deliver dementia awareness training throughout the year for primary care staff (GPs/ pharmacies), council staff and wider stakeholders. The workshop content includes:

- Understanding dementia, the signs and symptoms.
- How blood pressure, diabetes, obesity and high cholesterol impact on dementia
- Risk reduction of dementia through small changes in our daily lives.
- Signposting into local and national services.



### 3.1.5 Current services

NHS Health Checks are mandated to be provided by local authorities by regulations under the Health and Social Care Act (2012). The NHS Health Checks programme which includes dementia awareness, supports the councils prevention agenda and is the foundation of cardiovascular disease, diabetes and dementia prevention.

Dementia awareness is a core component of the NHS Health Check. Every patient aged 40–74 who has a NHS Health Check is made aware that the risk factors for CVD are the same as those for dementia -promoting 'What's good for the heart, is good for the head!' Up to 35% of dementia is preventable through modifiable risk factors, including physical activity, healthy diet, reduced alcohol intake and not smoking. As part of the check, patients aged 65 to 74 are made aware of the signs and symptoms of dementia.

#### Public health campaigns

Public health have run campaigns using the "Cares for a healthier borough branding", delivering the 'Think Brain Health' and other national campaigns, and included increased access to physical activity in the Public Health [Adult Physical Activity Plan](#) as well as building on existing physical activity opportunities and assets such as the Friendly Parks for All Project.

#### Dementia Awareness Training

Dementia awareness training is mandatory for primary care staff who deliver the NHS Health Checks service (GPs and pharmacies). In 2019, Richmond Public Health expanded the dementia training offer to the council and wider health and social care workforce. The course content includes:

- Understanding dementia, the signs and symptoms.
- How blood pressure, diabetes, obesity and high cholesterol impact on dementia.
- Risk reduction of dementia through small changes in our daily lives.
- Signposting into local and national services.
- Promotes the opportunity to become a dementia friend.

Since 2019, ten dementia awareness training workshops have been delivered (151 attendees) with post training evaluations of 91% of attendees stating their knowledge base was increased. Participants are also encouraged to sign-up and become a Dementia Friend.

Members of Dementia Friendly Richmond have access to Dementia Friends training through the coordinator or Alzheimer's Society's Dementia Friends programme. It is the biggest ever initiative to change people's perceptions of dementia. It aims to transform the way the nation thinks, acts and talks about the condition. Whether you attend a face-to-face Information Session or watch the online video, dementia Friends is about learning more about dementia and the small ways you can help. From telling friends about the dementia Friends programme to visiting someone you know living with dementia, every action counts.

#### Dementia Awareness Measure (DAM1)

Following the success of the training, a Dementia Awareness Measure (DAM1), based on the validated cancer awareness model, was developed in 2021. Deployed across Richmond and Wandsworth councils' Shared Staffing Arrangement (SSA), the aim of the DAM1 was to measure current knowledge and awareness of dementia among the SSA workforce. The DAM1 consisted of 25 questions, which were grouped into themes: risk factors, risk reduction, signs and symptoms, and questions to gather information about DAM1 responders; demographic information and SSA employment data.

#### Key findings from the DAM1

- The DAM1 was undertaken by 8% (328) of the council workforce (the SSA). Participation was not equally distributed among all Directorates within the SSA. Minority ethnic groups were underrepresented.
- The most common reasons for delayed diagnosis were, difficulty in making a GP appointment, worry about what a GP might find, fearing the diagnosis and having other things to worry about.
- Understanding of symptoms and protective factors varied with some more likely to be identified than others.

**Alzheimer's Society Richmond:** This team of dementia experts give tailored one-to-one psychosocial support to people with dementia, their families and unpaid carers, working with families for as long as they wish. They give advice and information about changing dementia symptoms, future planning, emotional adjustments and living well with dementia. There are also two weekly peer support groups for people with dementia, a weekly group for people diagnosed under 65 and a monthly peer support group for carers of people diagnosed under age 65.

**Adult Social Care Team- Front door:** The Adult Social Care Team provide information, advice, and signposting at the front door on topics including NHS and voluntary sector services, benefits and money management advice. Their work includes co-production to ensure a range of practical solutions and psychosocial interventions are readily available. This means the service is able to consider, respond to and meet the cultural needs of residents with dementia.

**Community Dementia Clinical Specialist (provided by Hounslow and Richmond Community Health care HRCH):** This is a primary care dementia nurse led service providing support to GPs for patients with dementia in the community. Nurses and practitioners bridge the gap between secondary care dementia services and GPs. They provide a professional confidential service to support both patients and carers to live well with dementia. They respond to a GP referral within 48 hours. The aim is to provide an appointment for a home visit within five days of receiving a referral to assess the patient and carer's needs.

**Dementia Friendly Richmond (DFR):** DFR aims to encourage everyone to share responsibility for ensuring that people with dementia feel understood, valued, and able to contribute to their community. It encourages businesses, voluntary and statutory organisations to commit to an annual action plan. This plan comprises two tailored action points, with the intention of making Richmond a more dementia friendly borough. Funded by the Council and led by Age UK Richmond (AUKR), the DFR Co-ordinator works with the business or organisation to set and achieve action points, and brings all members together to share, learn and promote activity.

A key action of DFR is to build on the initial success of the Richmond Dementia Action Alliance (RDAA) and learn from challenges the alliance faced in terms of sustainability and resourcing

A Dementia Friendly Richmond is an example of strength-based commissioning as its key role is to optimise, increase and harness community assets. Most people who live with a diagnosis of dementia in the community are living with an unpaid carer. Dementia Friendly Richmond not only creates better lives for people with dementia but also for their unpaid carers.

**Dementia Adviser, Barnes:** The adviser works within the Memory clinic five days a week. This is subcontracted by the CCG to South West London St George's Mental Health Trust who provide the support and supervision requires.

**Dementia Services Directory:** This directory is a valuable resource which gives information on local and national dementia support services and resources. It also provides a prompt for when you start to think and talk about what matters to you to live well with dementia. It may help you to discuss and consider your wishes and plans for the future.

**Richmond Carers Hub Service:** The Richmond Carers Hub service is a group of local organisations commissioned by the London Borough of Richmond upon Thames and the NHS to provide services specifically for carers in the borough. Richmond Carers Hub, includes over 420 carers of people with Dementia. Crossroads Care run a twice monthly Caring Café as part of the hub. Homelink also run a support group for unpaid carers of people with dementia in the hub and offer a Carer Support Service that offers emotional support and peer activities.

**South West London St George's Mental Health Trust Dementia Services:** Under this service there are specialist services and interventions for people with dementia.

**Richmond Memory Assessment Service (MAS):** The memory service is for people in Richmond presenting with symptoms of mild to moderate dementia who have not already received a diagnosis. GPs refer their patients who are displaying memory problems to MAS if they suspect it may be the sign of a mild to moderate dementia and impacting on the person's day-to-day functioning.

**Woodville Day Centre:** Woodville Centre is a local authority run specialist day centre for adults aged 60 and over who have been diagnosed with moderate to severe dementia. Woodville Centre provides care in a safe, secure and relaxing environment. It focuses on sensory stimulation and combines services to help people stay as independent as possible for as long as possible.

**Young person with Dementia Service in Richmond:** A Young Onset dementia worker is funded for 2 days a week to engage with the young people with dementia and their families in Richmond upon Thames. They offer one to one support as well as advice and information. They also raise awareness of Young Onset Dementia across the borough, and with wider health services and local organisations.

**Friendly Parks for All:** The parks team at LBRuT have actively been engaging with people with dementia and their carers through their Dementia Friendly Parks programme and the Friendly Parks for All project.

Parks are significant cultural assets for the borough and free to access for residents. They offer opportunities for exercise and to meet friends or local people. This is important for people with dementia and their carers who experience social isolation. This project aims to break down the barriers for people with dementia to benefit from spending time in their local parks and open spaces.

A good example of a Friendly Park for All developed for people with dementia and their carers is Heathfield Recreation Ground. The parks team worked with the Alzheimer's Society to design an outdoor gym that was suitable for people with dementia. (The principles for this have subsequently been used in other parks e.g. Carlisle Park). The path network was improved and a sensory trail around the park – a guide for this is on the council website or the app Go Jauntly.

The Friendly Parks for all team worked with Richmond College students to design a sculpture that was inspired by and for people with dementia. It is a huge armchair in steel that depicts feeling safe and home. The idea of this is to have a focal point for people who get confused. In other parks we have also marked entrances/exits with art work using information from the original consultation. The principles developed here were used in other 5 parks that have become Friendly Parks for All.



# PATHWAY PHASE ONE

## Strategic objectives

### Short term - two years

- To audit the dementia training available, identify what it covers, and ensure it meets identified need in Richmond.
- To strengthen dementia awareness training, with an emphasis on improving understanding in areas where knowledge was found to be lower., in particular, risk reduction messages. Changes in knowledge and awareness among the SSA and public will be measured over time.
- To have increased awareness of dementia within the community.
- To have increased awareness of the support available to people with dementia and their carers.
- To ensure that all people living with dementia and their carers have access to universal healthy lifestyle services.

### Medium term - five years

- To have incorporated relevant strands from the national strategy.
- To have all council owned and commissioned leisure centres dementia friendly

### Long term - ten years

- Continued awareness and training in the community that reflects new research



## 3.2 PATHWAY PHASE 2 Diagnosing dementia well

### 3.2.1

#### What do we mean by diagnosing dementia well?

Timely diagnosis of dementia is vital. It allows the person with dementia to be actively involved in decisions about their future life and care and facilitates access to interventions that may improve their condition or situation.

#### Diagnosing well

- Through our population health work and population health approach Primary Care Networks, PCN s will be able to systematically identify the people with dementia and refer into services that will best support them.
- Carers of people living with dementia are offered information and support relevant to their needs, throughout their experience with dementia.
- Specialist dementia nurses (Admiral nurses) working within HRCH dementia service to offer Tier 3 support to carers through proactive intervention and training to prevent crisis and family breakdown leading to care home placement or hospital admission.
- Admiral Nurses will work with carers to build on their own support networks to live well and keep physically and emotionally healthy.
- Carers will feel informed and equipped to care for someone living with dementia and feel able to plan, or flex to increased needs or challenge.
- Through IAPT carers will have access to psychological interventions.
- Our Carer's hub will work with Carers to enable them to access a range of opportunities to take a break from their role as a Carer.

There is a clear diagnostic pathway for dementia in Richmond. All Richmond residents and those registered with a Richmond GP have good access to the Memory Assessment Service (MAS) provided by South West London St George's that specialises in the diagnosis and initial management of dementia.

Once patient is referred to our Memory Service, >85% of the people with dementia will be diagnosed within 6 weeks. Signposting to other organisations is arranged through collaborative work with Alzheimer's society and Community Dementia Specialist Team, among others.

#### Young Onset Dementia

People with young onset dementia generally have some different needs compared with people with dementia who have developed their condition over the age of 65 years. However the numbers of people with young onset dementia within a borough are quite small compared with those over 65 years. This is why planning is probably more appropriate for this group (young onset dementia group) at a SWL level - rather than Richmond only.

#### Diagnosing dementia

**"This is quite a complex issue, not straight-forward at all. In my experience, a significant number of people with dementia never accept they have dementia or just don't recognise they have dementia.**

**This issue can be really difficult for family carers who are living with an individual who lacks awareness or insight into their condition. This can be particularly difficult in the early stages of dementia."**

**Margaret**

### 3.2.1

## What do we mean by diagnosing dementia well?

Our Goals	What we will do	Impact Statement
<p>We aim to improve the dementia diagnosis rate in Richmond to meet the benchmarking standard (66.7%) and the South West London ICB standard (70%) and to maintain that standard.</p>	<ul style="list-style-type: none"> <li>■ Increase awareness of the early signs of dementia through training in nursing home, residential care, health care and voluntary care settings.</li> <li>■ Dementia community practioners and Admiral nurses will work together on prevention, early diagnosis and pre and post-dementia diagnosis support for families.</li> <li>■ Continue to work with GP Practices on Quality and Outcome framework (QoF) registration and coding of new patients.</li> </ul>	<ul style="list-style-type: none"> <li>■ Richmond Borough will maintain benchmarking dementia standards.</li> <li>■ People will receive timely diagnosis.</li> <li>■ Richmond is a dementia friendly environment</li> <li>■ GP practice diagnosis rates will increase through early detection.</li> <li>■ The person and their family will receive pre and post diagnostic support.</li> <li>■ We will see a more accurate account for people with dementia locally.</li> </ul>
<p>To offer all those referred for a memory assessment pre-diagnostic support information and post-diagnosis support.</p>	<ul style="list-style-type: none"> <li>■ The person and their family will receive an information pack on dementia prevention and support.</li> <li>■ The Dementia Directory to be given a the point of a confirmed diagnosis.</li> <li>■ Refer to a dementia advisor to walk the person and their carer through the process and who to access help when required.</li> </ul>	<ul style="list-style-type: none"> <li>■ The person and their family will feel supported and held by the system during the process.</li> <li>■ People will feel empowered to care for the family member with dementia.</li> <li>■ The person and the carer will know who to contact should they need support.</li> <li>■ Carers will receive a care assessment yearly.</li> </ul>
<p>To provide timely accurate diagnosis as well as a care plan and review within the first year.</p> <p>To offer all individuals diagnosed with dementia access to support services which are personalised to their individual needs.</p>	<ul style="list-style-type: none"> <li>■ The person and the family will have relevant information at the point of diagnosis at review. i.e. dementia Directory which will enable them to navigate to the help and support they need.</li> <li>■ Enable a streamlined pathway from dementia diagnosis to support services for both the individual affected by dementia and the individual's loved ones and/or carers.</li> </ul>	<ul style="list-style-type: none"> <li>■ NICE standard access to care will be expected.</li> <li>■ Each person with dementia will have a care plan detailing their treatment options.</li> <li>■ Each person would be seen within 6 weeks for an initial assessment.</li> <li>■ The person and family will have access to a personal health budget to plan and arrange the support they need to keep the person at home.</li> </ul>

### 3.2.2 Evidence underpinning the strategy

The psychological and physical impact on the family of a person diagnosed with dementia is significant, especially on family members who take on the responsibility of caring for the person. Diagnosis can be a difficult time for the carer as well as for the person receiving the diagnosis.

The condition can have a major impact on their relationship as the person becomes more dependent on others and in the later stages may develop behaviours that challenge the family structure. Working in partnership with the carer can achieve better outcomes for the person with dementia and ensure services have a fuller picture of the person's needs.

People caring for someone living with dementia will feel informed and able to support their loved one, whilst able to maintain their own health and wellbeing.

The need to raise the profile of dementia amongst disadvantage group such as:

- People with a learning disability.
- People with Down's Syndrome.
- Black and minority ethnic groups.

#### **Diagnosing dementia amongst people with learning disability:**

People with learning disabilities have a higher risk of developing dementia than other people and usually develop the condition at a younger age.

This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50s. Symptoms of dementia can present differently so that people often don't recognise changes as being dementia related. Because of this, opportunities for early intervention are lost.

In Richmond the Your Healthcare Learning Disability Service will provide screening for this group. More work is required to ensure this group is supported and provided with relevant information in accessing help pre and post diagnosis of dementia.

We have found that mainstream diagnostic services are not geared up to assess people with learning disability. Likewise, mainstream dementia services are not geared to support people with learning disability or their carers. According to QOF data, in 2016/17 there were 586 people, known to a Richmond GP, who are affected by a learning disability.

#### **Recognising those disproportionately affected**

According to the Richmond needs assessment (2019) certain ethnic groups are disproportionately affected by dementia, however the degree to which the environment and genetics are responsible for this difference is unclear.

Understanding the cultural heritage of individuals living with dementia, enables high quality, safe, person centred care that focuses on the individual rather than the disease, and an understanding of challenges that may be rooted in a person's cultural background.

Establishing links with culturally-appropriate voluntary and community groups as well as interpreters who can support communication with families will provide the opportunity to discuss diagnosis and treatment options within the population.

The most recent Memory Clinic Audit by the Royal College of Psychiatrists found huge variation in waiting times from GP referral to diagnosis. The time between referral and diagnosis varied from three to 34 weeks, meaning that many people wait over six months to receive a diagnosis

There is anecdotal evidence from carers that GPs are reluctant to refer someone with possible dementia to secondary care and therefore the individual misses the benefit of early support following diagnosis.

Alzheimer's Society highlight the evidence for increasing memory service access to Picture Archiving and Communication Systems (PACS). When considering that neuroimaging investigations are often a key factor in the time it takes to receive a dementia diagnosis (and subtype diagnosis), a lack of access to PACS software for memory services can act as a barrier to timely and accurate diagnosis. Also, considering the focus given to complex cases that neuroimaging techniques are often employed in the diagnosis of, it seems strange to have omitted this.

They state that "Ensuring access to PACS for memory services to interpret alongside a patients clinical profile, and formalising arrangements for multidisciplinary/joint working will help facilitate a more accurate and timely diagnosis".

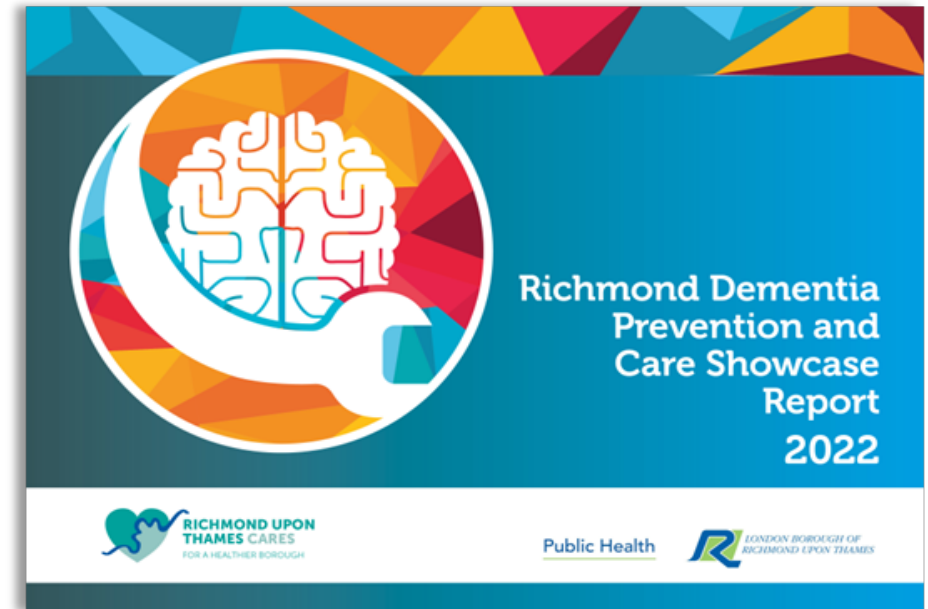
### 3.2.3

## What we have achieved since the last strategy

### Priority Phases 2, 3 and 5. Diagnosing and supporting people with dementia and those who care for them.

This work is led by the Clinical Psychiatrist for South West London and St George's Mental Health Trust and the Senior Transformation Manager South West London Clinical Commissioning Group.

- Ensured ongoing GP involvement and accountability by continued focus on dementia diagnosis and care delivered and led by Richmond GP and Clinical lead older people, frailty and mental health and Clinical Director, Cognition and Mental Health in Ageing as an important topic to peers through educational events etc.
- The NHS and local General practitioners and other clinicians worked closely with the Memory Assessment Service (MAS) to improve content of referrals to the Memory Assessment Service & Older People Service include sharing audit of referrals with GPs and the development of a new referral form for MAS was put in place in 2021.
- A Dementia Directory was produced which is given at the point of diagnosis to the person and their carers. It enables the person to make contact with relevant services to access help and support when they feel ready to do so.
- Richmond dementia diagnosis rate was on target at 67% and above in 2021, and rates continue to be monitored. The Richmond Integrated care service ICS continue to work on opportunities to improve diagnosis rates as well as recording and reporting of the data.
- An online young onset dementia (YOD) seminar session for GPs was held in early November 2021 designed to increase GPs awareness of signs and symptoms of young onset dementia and to share the lived experience of younger people living with dementia and their care partners. Alzheimer's Society continue to provide a service to the young onset dementia Richmond population in 2021/22, with a focus on pathway access for this group.
- The NICE recommended treatment Cognitive Stimulation Therapy has started in the Older People Service for people with dementia, promoting cognition, independence, and wellbeing.





### 3.2.4 Pathway mapping

#### Diagnosing dementia

Person or a family member of choice is worried about memory or other dementia symptoms (perceptual, visual, cognition etc) and seeks consultation appointment with GP.

Young Onset Dementia (YOD) – Concern about your memory, please see GP to rule out depression or a physical cause. Memory clinic referral to be considered.



GP: takes full history and tests to rule out other causes of symptoms eg delirium or UTI infection. May include blood pressures, blood and urine tests, mini-cognitive test for dementia. Once further investigation is completed GP refers to Memory Assessment Service,(MAS) for further screening and tests for dementia.



Richmond Older Peoples Mental Health Community Services runs the NHS SW London & St George's Mental Health Trust Memory Assessment Service (MAS) based at Barnes Hospital and in the community.

**MAS:** undertakes initial assessment (History taking from patient and relative/friend, Mental State Examination, Cognitive test)

**Further Assessment involve:** (Head CT scan/MRI (Hospital), neuropsychological assessment (by Psychologist in clinic), referral to neurologist, and functional assessment as appropriate (by an Occupational Therapist at home).



**Diagnosis Appointment:** If dementia is present the MAS clinician discusses the diagnosis and type of dementia with the patient and a family member of choice. (Alzheimer's, Vascular, Mixed, Frontotemporal, Lewy Body dementia)

**Written information provided:** Includes a dementia Information Pack, Richmond Dementia Directory, links to the council's online Dementia Directory.

**MAS specialist:** Will explain any treatment options, including medication and Cognitive Stimulation Therapy other therapies if appropriate. MAS provides follow up care for a period, depending on the patient's health. A referral is made to the Alzheimer's Society Dementia Adviser service for specialist psychosocial dementia advice and information. Referral to Social Services, and Voluntary Services are



Pharmacological: Medications may be prescribed and once a person's condition is stable MAS discharges to GP. If behavioural and psychological symptoms develop, GP may refer to Hounslow and Richmond Community Hospital(HRCH) community dementia service or back to the Community Mental Health Team (CMHT) depending on severity and needs for further pharmacological management. HRCH Community dementia Service will supports families with communication and coordination of care by liaising with other services such as GPs, Alzheimer's Society, Adult Social Care and other voluntary and statutory services based on needs.



Patients with a given dementia diagnosis can be re-referred directly to CMHT by HRCH and Alzheimer's Society in the case of moderate to severe behavioural and psychological symptoms of dementia.

## 3.2.5 Current services

### Memory Assessment Service (MAS)

The memory service accepts referrals from Richmond GPs, geriatricians, neurologists and hospitals. This includes residents of care homes and nursing homes from the borough. Most people referred into the service are seen within 6 weeks for an initial assessment and provisional diagnosis.

Further investigations like a Head CT Scan, neuropsychological assessments or functional assessments may be arranged before a dementia diagnosis (and subtype of dementia) can be confirmed. Carers are encouraged to attend the memory clinic and to be a part of the diagnosis.

MAS specialist will explain any treatment options, including medication and Cognitive Stimulation Therapy other therapies if appropriate. MAS provides follow up care for a period, depending on the patient's health.

Some referrals are made to the memory clinic services provided by the West London Mental Health NHS Trust, usually due to geographical proximity. In addition, GPs are able to make a diagnosis themselves where appropriate, without referral to the memory clinic, in cases of advanced dementia. A small proportion of diagnoses occur in secondary care, for example while someone is an inpatient in hospital, and in most cases the patient's GP is informed of the diagnosis when the individual goes home.

When people receive their diagnosis at the memory clinic, they and their carer are provided with both verbal and written information about their condition and any possible treatment, including medication and Cognitive Stimulation Therapy group (when appropriate).

### Referral to other services

All those newly diagnosed are referred to the Dementia Advisor, provided by the Alzheimer's Society, who sits within the memory clinic and acts as an information navigator following diagnosis. The referral is made to the Alzheimer's Society Dementia Adviser service for specialist psychosocial dementia advice and information. Referral to Social Services and Voluntary services.

Those diagnosed at the memory clinic and their carers have access to the Dementia Care Advisor on an ongoing basis to aid them in accessing services in the area, and local GPs can also refer individuals diagnosed elsewhere to that service.

### General Practice

In Richmond, initial management of newly diagnosed individuals is provided by the memory clinic. Follow-up care is transferred back to the GP once the individual's condition is stable and their medication regime is well established..

Patients can and should book annual GP dementia reviews themselves in with their practice. Some GPs may not specifically call the consultation a dementia review or care plan as they may happen opportunistically or as part of another review, such as a frailty review.

## PATHWAY PHASE TWO

### Strategic objectives

#### Short term - two years

- For all Richmond GP practices to achieve the national dementia target for earlier diagnosis -NHSE 6-week referral to assessment target.
- To reduce the gap between those diagnosed with dementia and people who are not diagnosed but living with dementia.

#### Medium term - five years

- To have incorporated relevant strands from the national strategy.

#### Long term - ten years

- To have a decreasing trend in the incidence of vascular dementia in Richmond



## 3.3 PATHWAY PHASE THREE Support after diagnosis

### 3.3.1 What do we mean by support after dementia diagnosis?

Support after diagnosis is a particularly important stage in the dementia pathway. Due to the progressive and unpredictable nature of dementia, people will encounter a range of services and meet many different health and social care professionals. This can be confusing for the person and the care they receive can often feel disjointed.

While information can go some way to ease these challenges, more proactive person-centred support in the form of a care coordinator would better help a person living with dementia to navigate this complex system. Identification of a care coordinator must happen towards the beginning of the pathway, either by a memory clinic or by primary care during a follow-up appointment.

Family and friends are often affected by the need for provision of additional care and support for individuals with dementia. Many people take on the role of informal carers, carers that are not paid for their services. This results in additional personal strain for them in addition to a potential loss of earning as they often must remain at home to care for their loved ones. Alzheimer Society estimates that the percentage of carers caring for more than 100 hours per week has increased from 40% to 50% since March 2020. In a wider context, Carers UK's estimates that the average carer is now spending 65 hours a week on caring responsibilities.

Dementia reviews are contained under the QOF, a pay-for-performance scheme aiming to improve the quality of care patients receive by rewarding practices for the care they provide.

Hospitals and inpatient settings have been encouraged to make their environments dementia friendly and communities have been working to create dementia friendly towns and villages.

### Community advice and support

Richmond Council Adult Social Care First Contact and Community Advice and Support teams provide residents with dementia and their unpaid carers with information about care and support services available locally including: The types of care and support available

- How to access care and support including eligibility criteria
- How to get financial advice about care and support
- Local safeguarding procedures and how to raise concerns or make complaints
- Rights and entitlements to assessments and care and support services
- Personal budgets and options available for taking these, e.g. local authority managed or a direct payment
- Independent Advocacy
- Community resources including voluntary sector, user-led organisations, and available housing options.

### Assessments

If a resident will benefit from an assessment of their social care needs, they are provided with independent advocacy if they need this to enable them to participate. The Council will consider the person and their family or informal carer's preferences in terms of the time, date, and location of the care assessment, and conduct the assessment face-to-face unless they prefer a different method of assessment.

- The assessment focuses on their needs related to their dementia and any other conditions they have, and how they impact on their well-being, and the outcomes they want to achieve in their day-to-day life.
- Assessments involve the person and their family or informal carer in discussions and decisions about any care and support they might need. We aim to be transparent about why and when decisions about care and support are made. They are respectful of their dignity and consider their personal history and life story, the needs of their family or informal carers, their housing status and where and who they want to live with, are aimed at promoting their interests and independence and take into account the negative affects of social isolation on their health and well-being.
- The assessment will take into consideration available information and recommendations from NHS partners about the resident.

## Caring and unpaid carers

A resident's unpaid carer will also be offered an assessment to discuss their caring role and how it impacts on their life. Support can be offered including:

- respite care to for a a break
- information on local support groups
- help with caring
- equipment to help with caring

Social workers receive training around dementia and those in the community are very aware of how people seek to hide their dementia. Social workers use a number of methods to check out the reality of what is being said, by asking the same questions differently and checking out statements with informal and formal carers. Council Adults Social care, Adult Social Care Academy is working with SWL team around for future training around dementia, and dementia awareness. Statutory and Care Home staff

The council has a dementia Lead who regularly communicates with the Alzheimer's Society. Each team have local knowledge of groups that support residents in their local area. Information is held via RUILS/CILS, the Front Door Project etc.

Discussions regarding a living Service Directory is taking place within all professional parties, as well as acknowledging the need to ensure that the information held is current and correct. There will be a drive to encourage more Managers and staff members to become Dementia Friendly accredited.

Information regarding the various care and specialist support provided for individual care home is held and managed by Care Quality Commission (CQC), who are an independent body, they undertake the relevant care home audits and monitors the results for any improvements. All Care Home and Service Providers are also governed by the Care Act 2014, and where concerns are raised a Safeguarding Concern is formally raised. Safeguarding means protecting an adult's right to live in safety, free from abuse and neglect.

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All Care Home and Service Providers are also governed by the Care Act 2014, and where

concerns are raised a Safeguarding Concern is formally raised.

Safeguarding means protecting an adult's right to live in safety, free from abuse and neglect. It is about people and organisations working together to prevent and stop both the risks and experience of abuse or neglect, while at the same time making sure that the adult's wellbeing is promoted including, where appropriate, having regard to their views, wishes, feelings and beliefs in deciding on any action. This is a multidisciplinary function where professionals , family members, the individual and their advocate are active participants

The HRCH Directory of services provides information about dementia services and highlights all 'points of entry' into health and social care.,More could be done with wider teams such as housing and local authority to ensure wider health and social care services have knowledge of where and how to signpost people to the right dementia services in order to improve patient flow and timely support.

### 3.3.2 Evidence underpinning the strategy

Once a diagnosis is made a multidisciplinary team should be involved. Good practice indicates a need for a formalised processes to enable multidisciplinary team meetings between the various parties, or feedback channels between primary and secondary care.

Establishing a clear pathway, with joint working arrangements in place, helps to facilitate communication between all professionals involved in the diagnostic pathway. The ere is also a need for a range of information from across the dementia system.

Dementia UK recommends that clear and accessible information about funding such as NHS continuing healthcare (CHC) is easily available to residents, and that there is support available to help families navigate the process. It is also vital that health professionals, including CHC assessors, have understanding and knowledge of dementia to ensure CHC assessments are fair, transparent and fully recognise the needs of the individual.

There is clear and accessible information about NHS fully funded continuing healthcare available to all residents and their families on the [NHS website](#).

There is reference to CHC in the [Richmond Dementia Services Directory](#) on the Council website advising residents and families who think they might be eligible for CHC to discuss it with their GP, Community Nurse or Social Worker, who can support with making a referral to the ICB, if indicated.

### 3.3.3 Pathway mapping

The post-diagnostic support pathway for people with dementia follows diagnosis by a specialist – usually a memory assessment service – who may also provide immediate support after diagnosis.

Depending on the type of dementia diagnosed, people will then be discharged from the memory assessment service to their GP who will take over their ongoing care and support.

#### Supporting after a diagnosis: Living well

**Financial and legal:** Richmond AID/ AgeUK/ Richmond Adult Social Care provide financial and benefits advice eg Blue Badge, council tax discount, carers assessments, attendance allowance. Legal planning via RAID/ Alzheimer's Society for making power of attorney and wills while a person's mental capacity and cognition is appropriate.

**Health:** Opticians, audiology and dentistry needs must be met to optimise comfort, communication and reduce isolation. Speech therapy is available via INS Richmond. Support may be needed to attend appointments, assisted by community befriending services (to be commissioned). GP does annual review and supports person to set up Urgent Care Plan to ensure medical data sharing across front line teams and capture end of life and resuscitation wishes. Encourage 'This is Me' document to facilitate communication.

**Safety and mobility:** Adult Social Care team to arrange suitable package of home care and home adjustments (eg grab rails, ramps, telephony, IT, smoke detectors, fall alarms) to retain independence at home. Falls prevention via HRCH Falls and Bone Health Service. Encourage family to register with Metropolitan Police Herbert Protocol reduce risks to missing persons.

**Advice and information:** Carers Information and Support Programme; Living Well with Dementia Programme; peer support for people with dementia and for carers of a person with dementia; Alzheimer's Society specialist young onset dementia support service. Richmond Carers Centre supports unpaid carers

**Living well:** Accessible amenities include Richmond Community Independent Living Service (CILS) Neighbourhood Care Group activities; AgeUK exercise sessions; nature walks; arts and crafts; dementia cafes; music. People may engage in dementia research by participating in clinical trials and studies. Dementia Friendly Richmond project to encourage retail, faith, leisure and cultural opportunities.

**Changing needs:** GP's annual checks serve as baseline for medications reviews. RB Mind counselling for mental distress and adjustment. Respite via day centres at Sheen Lane, Woodville Centre, Homelink. Community respite via Crossroads Care or private providers. Alzheimer's Society Dementia Support services for self referrals at any time.

### 3.3.4 Current services

#### Hounslow and Richmond Community Healthcare services (HRCH) Community Dementia Service

The originally created following a CQUIN with Richmond CCG in September 2015 to support patients registered with a Richmond GP Practice. HRCH's Community Dementia Services is a multidisciplinary team.

From 2016–2019 it was funded by HRCH, moving to a contracted service with a service specification from Richmond CCG in April 2019. The Hounslow CCG have separately commissioned an Enhanced Dementia Service that supports those living within the borough of Hounslow. As the Hounslow service has different criteria and commissioners these are not included within this strategy.

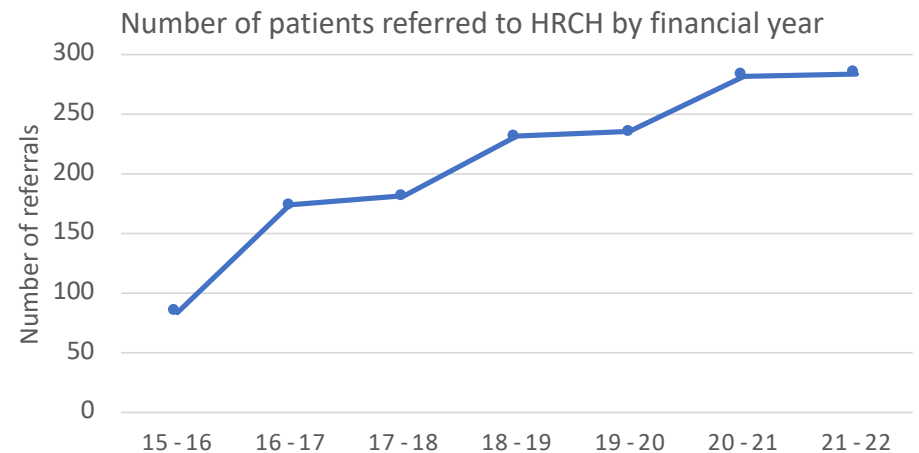
The aim of the Richmond service is to promote independence at home according to the persons level of ability, improving the service and quality of care for patients living with dementia and their carers. The service aims to improve communication and coordination of care by liaising with other services such as GP's, social services and other voluntary and statutory services. It is delivered by the community dementia practitioners. They bridge the gap between secondary care, social care & the GP.

The service has several components:

- Patient caseload
- Supporting carers
- Teaching staff
- Working within HRCH to promote dementia care within all services and to encourage dementia friendly clinical environments
- Networking and liaising with external stakeholders and the wider health service.

#### Trend in referral rates

- Since its creation in 2015, the referral rate for the service has risen steadily (see chart below). This increased dramatically during the COVID-19 pandemic when informal family carers struggled without respite from day centres and paid care staff.
- During 2020-21 and 2021–22 the service has seen on average 23 referrals per month. To date in 2022-23 it is averaging at 20 referrals per month.
- The number of patient contacts increased dramatically during the COVID-19 pandemic to an average of over 90 contacts per clinician per month and have not returned to pre-COVID-19 level.
- The number of contacts reduced slightly in 2021 – 22 due to long term staff sickness leading to 2 months of part time staff only within the team.
- The Service currently consists of 1.6 WTE clinical staff and 0.6 WTE part time administrative support. Since June 2022 they have been supported by a Bank staff member for 15 hours a week. It is not possible to maintain this level of service without increasing the current staffing levels.



## Plans to support those living with dementia and their carers post diagnosis:

- HRCH's Community Dementia Practitioners are a multidisciplinary team (currently an OT and a nurse). Over the next two years Admiral nurses will work alongside HRCH community dementia practitioners to provide early prevention, timely diagnosis, training for staff and support for carers.
- They will produce well defined dementia pathway from prevention to end of life care. Community dementia specialist support.
- All people with dementia will receive timely support to reduce the risk and manage crisis. both the person living with dementia and their carer to ensure health & psychosocial needs are met.
- People with dementia and their family will have access to personal health budget to manage their care.
- If they and their carers would like to, people could stay in their home for longer with the necessary support built around them and their carer.
- People with learning disability, autism and Down's syndrome will have adjustments to support ensure they have access to the dementia care they need. Easy read information will also be made available for where possible.
- A dementia awareness training programme will be made available to care staff and frontline staff across the borough. The HRCH Dementia Service is commissioned to provide an annual GP training session but this has not occurred for 3 years due to the COVID-19 pandemic.
- Dementia Assessment Referral to a GP (DeAR-GP) tools will be re-invented across care homes and residential homes to identify early cases of dementia.
- A referral pathway between HRCH and secondary care will improve the dementia pathway flow, promoting a seamless interface between memory services, community mental health trust, primary care, nurses and the dementia advisor. This will minimise delays in dementia diagnosis and treatment, care support and crisis prevention and interventions.
- Carers of people living dementia are offered information and support relevant to their needs, throughout their experience with dementia.

- Admiral nurses working within HRCH Community Dementia Service will supplement the current team working with tier 3 support to carers.
- Admiral nurses will work within the current team to increase the support offered and work with carers.
- Specialist community dementia practitioners working within HRCH dementia service to offer Tier 3 support to carers through proactive intervention and training to prevent crisis and family breakdown leading to care home placement or hospital admission.
- Admiral Nurses will work with carers to build on their own support networks to live well and keep physically and emotionally healthy.
- Carers will feel informed and equipped to care for someone living with dementia and feel able to plan, or flex to increased needs or challenge.
- Through IAPT carers will have access to psychological interventions.
- The Council's Carer's hub will work with Carers to enable them to access a range of opportunities to take a break from their role as a Carer.





Anyone with dementia is entitled to an assessment of their needs by the local authority. This is called a care needs assessment. It should identify what the person's needs are, and what support would meet these needs.

### **Continuing Health Care, CHC**

Social Care First Contact Team can signpost to and provide information on CHC, and the Community Advice and Support Team can have a more in-depth discussion with a resident or informal carer about this. We will refresh this within the team to ensure the front door staff have good understanding and knowledge of dementia in relation to CHC

GPs, Community Nurses, Practitioners, and Social Workers who are involved in assessing residents with dementia consider if they might be eligible for NHS fully funded Continuing Healthcare and if so, facilitate the necessary assessment, which is jointly completed by Richmond Adult Social Care and HRCH. They are able to talk through the process with residents and their families and explain the criteria, which are not diagnosis specific but related to the impact of health needs on the person's ability, and how complex, intense, and unpredictable they are. The outcome of the assessments must be ratified by Richmond ICB and is provided to residents in writing as well as via the involved practitioner. There is a process of appeal to the ICB should a resident or their family not be satisfied with the assessment or its outcome.

The Adult All practitioners involved in completing the checklist with residents and their families, and in assessing for CHC have robust training in assessment of adults with complex disabilities including dementia and in fairly applying the CHC criteria and they are supported with continuous professional development in regular one to one supervision sessions.

### **Social Prescribing for people affected by dementia**

Social prescribing connects people to practical and emotional community support, through social prescribing link workers, who are based in GP practices and take referrals from agreed local agencies. Link workers have time to build trusting relationships, start with what matters to the person, create a shared plan and introduce people to community support. One of the criteria is having a long term condition. dementia falls into this category.

Examples of the support provided are:

- Housing benefit and financial and advice
- Employment, training and volunteering
- Education and learning
- Healthy lifestyle advice and physical activity
- Arts, gardening, creative activities
- Befriending, counselling and groups

The link workers carry out an assessment to:

- Identify needs, strengths, networks, outcomes, services to access
- Build rapport and start to create personalised plan
- Further research required and follow up to agree plan including needs, outcomes, timescale and support
- Ensure partnership working in putting a plan into place, signposting, referral, support to access services
- Provide information on waiting lists and identify gaps in provision
- Follow up with the patient to review progress, further research.

## Social Prescribing for people affected by dementia

### Case Studies - source RUILS

#### Case Study

Suzie and Charles are both 73 and they have just celebrated their golden wedding anniversary. They have led an active life, regularly going out for meals, drinks, theatre and walks.

They would do this together and individually with their own friends. Suzie has recently been diagnosed with mixed type dementia and she has become increasingly withdrawn and not as active.

Charles is finding it difficult to adapt to the change in Suzie and how it is impacting on his life. Suzie she has become increasingly withdrawn and not as active. She was referred to social prescribing to help with her social anxiety.

#### What Social Prescribing did

Met with both Suzie and Charles to find out what they enjoyed doing.

Worked with Suzie to fine out what was worried about when she went out.

Researched what was available locally that Suzie could attend by herself or with Charles, this included 1:1 walks.

Discussed finances and referred for a benefits check.

Met Suzie at a local art group that she could participate in.

Linked with Bares Hospital and Alzheimers society to join support groups.

Suzie and Charles were successful in their application for Attendance Allowance.

Suzie was supported on short walks with a volunteer and began waking around the park with Charles again.

Suzie discovered her long lost passion for art and was able to express herself through this.

Charles got a lot of information from the Alzheimers website and support groups.

Suzie and Charles got an Alexa from the council help remind them of appointments and Suzie used it when she was cooking.

#### Case Study

Grace and George are both in their early 60's and have recently retired from full time jobs. George was an architect and Grace a primary school teacher.

A few months ago George began to experience memory loss and word finding difficulties.

After a visit to the GP George was referred to the Memory service at Barnes Hospital and diagnosed with Altimeter's type dementia.

Barnes Hospital referred to the Altimeter's society for support.

George's mood became low and he had feelings of being useless.

Grace felt that she had to look after him and protect him and started to take over some of his roles in the home, which led George to getting frustrated.

#### What Social Prescribing did

Social prescribers met with George and Grace exploring hobbies and what they wanted to do.

George wanted to carry on doing things he had always done as long as possible, so was referred back to Barnes Hospital OT to work with different coping strategies for George and Grace.

A referral was made to Age UK to look at Lasting Power of Attorney for both of them and to check the situation of their will.

Grace was referred to Carers Centre for additional support and work out strategies for Grace to manage her frustration.

George enjoyed playing bowels and gardening and was referred to Ruils Bowling and Ruils allotment.

Referral was made to a well-being project for Grace to attend for six weeks.

Discussion with GP about George's low mood and prescription of low dose anti-depressants.

At the end of our intervention both Grace and George felt that they had more options. They had activities that they were able to join in and gave them a sense of independence.

They felt that they were in more control of their going forward.

## PATHWAY PHASE THREE

### Strategic objectives

#### Short term - two years

- For all Richmond residents with a dementia diagnosis to have co-produced Urgent Care Plan within a year of their diagnosis.

#### Medium term - five years

- For all Richmond residents with a dementia diagnosis to have co-produced Urgent Care Plan within a year of their diagnosis

#### Long term - ten years

- Increased SWL YOD post-diagnostic provision.



## 3.4 PATHWAY PHASE FOUR Enabling a fulfilling life with dementia

### 3.4.1 What do we mean by enabling a fulfilling life with dementia?

**Hounslow and Richmond Community Healthcare has a range of plans for supporting dementia care in the next 5 years.**

- To ensure all patients have a comprehensive assessment to create an individualised care plan that can be implemented throughout their dementia journey.
- To ensure all patients have a discussion to create an emergency and advanced care plan to reduce hospital admission.
- To improve patient outcomes by developing services in line with the 'NICE Dementia Guideline'.
- To improve patient experience by working to create greater integration across all statutory and voluntary health & social dementia services.
- To ensure that all carers have physical and mental health wellbeing screening to create an individualised care plan for themselves.
- To make dementia everybody's business by working to make dementia universally understood and improving the skills in their own and their partner's workforces.
- To maintain patient and carer engagement in order to continuously review and adapt the service to the needs of our population group.
- To engage in research opportunities to ensure the service provided meets the wellbeing needs of carers, especially in the community.

"We really need a team of dementia specialist nurses and para-professionals who could act as a named person for each individual with dementia and their carer, right through the whole disease process. To me, a named dementia support professional to provide support and co-ordinate care is a key priority if people with dementia and services are to be brought together effectively to enable as fulfilling a life as possible, both for the person with dementia and their carer."

Margaret

### 3.4.2 What we have achieved since the last strategy

This work is led by Adult Social Care Commissioners.

- In 2021, funding was secured as part of a one-off variation of the Carers Hub contract for short breaks, Seventeen carers of people living with dementia who had never accessed formal respite before were able to access 139 hours of respite between April and August 2021. The Carers Hub contract has now been confirmed until 2024 supporting short breaks for unpaid carers to March 2022. To date 42 carers of people living with dementia accessed the formal respite from Crossroads and about one-quarter of the 54 individual short break grants were for people caring for someone with dementia.
- A short-term contract was awarded to deliver one-to-one counselling to 25+ unpaid carers at risk of carer breakdown.
- A consultation with people living with dementia and their unpaid carers identified bespoke activities that will be delivered as part of the variation in the CILS Partnership.
- To support the council's emphasis on digital first, Adult Social Care are looking at how better to support residents with one off grants for digital tech which will help them live independently.
- There are currently 379 carers of people living with dementia registered with Richmond Carers Centre.

## Overall Summary:

- All recommendations about improvements to meet the changing landscape across prevention, diagnosis, and care of dementia in the context of COVID-19 were put in place following the successful workshop.
- A informative survey of the understanding of dementia awareness and lifestyle risk factors among Council staff has taken place.
- Dementia Friendly Richmond has been established to support local organisations and businesses to each commit to 2 action points that contribute to capability building and improving the experience of people affected by dementia and their unpaid carers.
- We are delivering a multi-agency and partnership approach to dementia care and support in Richmond. The Community Independent Living Service (CILS) run specialist one to one support for people with dementia and their carers and deliver a number of dementia specific groups including a monthly 'Forget me Not' pub lunch, art therapy course in Barnes and peer support group.
- A GP champion works between practices and nursing homes to screen for dementia.
- Hounslow and Richmond Community Healthcare services,(HRCH) production of a dementia Directory and 3 highly successful Positive Dementia Conferences for families, local voluntary & statutory services to share local & national initiatives.

## Evidence underpinning the strategy

NICE guidance states that , everyone diagnosed with dementia should have access to a named health or social care professional. This person is responsible for coordinating their care from the point of diagnosis to the end of life. During the early stages of the condition, this may involve signposting to services. In later stages, it may involve coordinating all aspects of the person's health and social care. The care coordinator role may be taken on by one of a variety of different health or social care professionals such as GPs, nurses, psychologists, occupational therapists, social workers and others.

## Dementia Friendly Richmond (DFR)

DFR is working with local organisations to ensure that their staff and volunteers are confident in approaching and talking to people living with dementia.

Funded by Richmond Public Health, and delivered by Age UK Richmond, Dementia Friendly Richmond (DFR) was launched to coincide with Dementia Action Week in May 2021.

Dementia Friendly Richmond aims to create an inclusive borough where all residents affected by dementia are empowered and supported to live well. It helps support those with dementia and their carers to:

- travel to where they want to go safely
- live somewhere they feel supported, understood and included in community life
- receive the help they need to access quality health, care and support services when and where they require it
- be able to participate in all that London has to offer in arts, culture and leisure
- feel confident to visit local high streets and town centres

A key focus of DFR is to encourage everyone to share responsibility for ensuring that people with dementia feel understood, valued, and able to contribute to their community.

It encourages businesses and voluntary and statutory organisations to commit to an annual action plan which comprises two tailored action points, with the intention of making the London Borough of Richmond upon Thames a more dementia friendly borough. The DFR Co-ordinator helps to set and achieve each action point, working with the individual business or organisation and brings all members together to share, learn and promote activity.

DFR aims to recruit 100 organisational members and train new dementia Friends across the borough by 2023 and develop a network of local organisations, supporting members to implement new initiatives and become dementia friendly, engage with people living with dementia and their carers, and work with the Council to help improve and develop services.

Maintaining the current level of dementia Friend partners means the current project is close to full capacity. Project coordination capacity will need to be increased throughout the length of this strategy in order to sustain an ambition over the course of the next 10 years for the LBRuT to have all services the Council provides or funds sign up to be members of DFR and commit to completing two action points.

### 3.4.3 Pathway mapping

#### Enabling a fulfilling life with dementia: Crisis management

**Home:** If crisis presents at home, a person with dementia or family member of choice may contact their GP for a medications review or Urinary tract infection, (UTI) check. Hounslow and Richmond Community Hospital, HRCH's dementia support team provides clinical advice in the community. Alzheimer's Society Dementia Support gives advice on coping with changing dementia symptoms. Adult Social Care support people if a care package is in crisis or an unpaid carer falls ill.

**Hospital admissions** are improved by planning ahead, eg ensure that Urgent Care Plan (including end of life wishes) is up to date, that a person has a packed bag containing key paperwork, medication, spectacles and dentures. A 'This is Me' communications preference list may be completed to ensure optimum care and that a person only tells their story once.

**Hospital:** for hospitals, clear communication is vital with families and community support providers throughout the admission process, hospital stay and on discharge. A named hospital staff member should be in charge of the patient's care and able to communicate with the family member of choice. Patients admitted to Kingston Hospital with dementia, delirium or cognition problems can be referred to the Dementia and Delirium Team. Phone: 07748 925 581 [khft.forgetmenot@nhs.net](mailto:khft.forgetmenot@nhs.net). The Dementia and Delirium team can inform any community teams of a patient's discharge.

Richmond Intensive Care and Support Team (ICST)(part of Richmond Older Peoples Mental Health Community Services) provides support during a crisis to reduce admission to mental health hospitals. They support patients and carers following discharge from a mental health hospital. Referrals must be from secondary mental health services.

HRCH's Richmond Response and Rehabilitation Team (RRRT) provides a rapid response to manage crisis and support people to stay at home, preventing unnecessary admission to an acute hospital or a residential/ nursing home. The team also supports early hospital discharge services to facilitate shorter hospital stays and ensure a safe return to a person's home.

After the crisis is managed and the person with dementia's situation is improved, the specialist teams inform the GP of treatments and medications updates.

## 3.4.4 Current services

### Hounslow and Richmond Community Healthcare (HRCH) Community Dementia Service

HRCH are impacting on crisis prevention and reducing hospital admissions for those living with dementia, enabling them to live at home for a longer period or until end of life in a state of wellbeing supported by family and paid carers.

The team vision for dementia care is 'enabling people to maintain quality of life at each stage of their dementia journey through high quality seamless care to maintain health & wellbeing'.

The team mission for dementia care is 'for inclusive and positive care to be available for everyone whose life is, or may be touched by dementia by developing skills for professionals and families'.

The service has several components comprising of:

- Patient support from pre-diagnosis to end of life.
- Supporting carers, teaching & supporting staff, working internally to promote dementia care within all services and to encourage dementia friendly clinical environments.
- Networking and liaising with external stakeholders and the wider health service.

### Some local services provided by DFR members

- Find Good Care helps people identify the care that is right for them.
- Strawberry Hill House run arts & crafts and gardening sessions.
- Creative Minds based at the ETNA Centre St Margaret's provide arts therapy.
- Hampton Mission Partnership: runs a Dementia Café.
- Crossroads Care run a caring café at Mortlake library with group support for carers and entertainment for people with dementia.
- Embracing Age provide companionship for people in care homes delivered by volunteers. Activities include reading with the person, assisting them with technology, taking people for walks and playing board games.
- Richmond Health Walks run walks specifically for people with dementia and their carers.
- Care agencies available include Visiting Angels, The Good Care Group, Right at Home and Crossroads.
- Homelink day centre provide respite care and carer support.
- Holly Lodge, a charity based in Richmond Park, welcomes groups of people with dementia for different sessions.
- Richmond Carers Centre, RUILS and FiSH (Barnes) all offer a variety of services which can include training carers and befriending schemes.
- Richmond Music Trust hold singing for the brain sessions.
- Friendly parks for all include a monthly accessible walk and wellbeing walk. These all park projects are designed with input from people living with dementia

# PATHWAY PHASE FOUR

## Strategic objectives

### Short term - two years

- Resident can access their support and care in a seamless manner.
- To have increased diagnosis of people living with dementia in care homes who are undiagnosed.
- To increase the number of community dementia clinicians and practitioner and team by two whole time equivalent staff.



### Medium term - five years

- To have all services the Council provides, or funds sign up to be members of DFR and commit to completing two action points annually.
- To have a range of digital and non-digital tools to support people with routine daily tasks.
- To have overseen a smooth transition from hospital care to health and social care.
- To have scoped a dementia Hub and have clear co-produced plans in place

### Long term - ten years

- To have incorporated relevant strands from the national strategy.



# 3.5 Overview of actions across the Richmond dementia pathway

The overview of the actions to be taken across the dementia pathway is presented in the table below:

Points of focus	Preventing dementia/ Risk Reduction	Diagnosing dementia	Supporting after a diagnosis of dementia	Enabling a fulfilling life with dementia	Ensuring dignity and comfort for those dying with dementia
<b>Awareness</b>	Increase awareness of dementia risk factors in the community and in the health and care system. Provide joint awareness raising for staff in the Local Authority and in the Care Homes.	Increase dementia recognition and referral/signposting amongst health and care staff.	Ensure all health and social care staff in the borough receive evidence-based dementia training.	Improve clarity regarding the dementia diagnosis pathway. •Build upon the achievements of Dementia Friendly Communities Richmond, maintaining participants and growing membership.	Increase awareness of the value of early advanced care planning. Increase awareness of dementia-related services in the borough.
<b>Access</b>	Ensure equitable access to preventative services for communities at higher risk of dementia.	Improve access to support services whilst awaiting a diagnostic decision. Improve signage so people are aware how to access information and support should they be concerned about dementia.	Ensure the person is given a copy of Dementia Directory to access services as and when they feel the need for the support.	•Improve consistency of access to primary care services for those living in residential care homes and nursing homes.	Ensure that carers and people with dementia can make future care plans in a setting of that suits them.
<b>Quality</b>	Increase provision of evidence-based interventions known to slow dementia progression	Improve the efficiency of diagnosis in local memory assessment services, to address the dementia diagnosis gap in care and nursing homes.	Establish a consistent, borough-wide, care plan process and ensure that there is a mechanism to ensure care-plan maintenance.	Improve understanding of achievements and unmet need in Richmond in relation to NICE guidance on dementia care Maintain and improve community dementia support networks.	Ensure that documentation of future care planning is standardised, accessible and regularly reviewed.
<b>Seamless pathway</b>	Ensure access to dementia information so people understand the link between healthy and active lifestyles and are able to make positive changes in their lives	Professionals across the system to be aware of referral pathways and to work together to best support the assessment and diagnostic process. Ensure all stakeholders are aware and given a copy of the dementia flow chart on pathway access.	Access to dementia advisors at the point of diagnosis to support the person and family through the pathway.	Work towards Improving the environment and physical settings in the community to be dementia friendly. Ensure people with dementia have access to respite care and alternative accommodation options as and when required	Ensure people living with dementia, their families and carers complete advanced care plans that are recorded and held by the GP Ensure people are informed of options about end of life and are given the appropriate support, respect and dignity to die in the place they choose.
<b>Digital and technology access</b>	Ensure people living with dementia and their carers can access digital healthy lifestyle intervention, communication and messages	Professionals across the system to be aware of technology available to support people with dementia Ensure technology is included in dementia pathway flowcharts.	Establish a simple and consistent process for the assessment and provision of technology across all partners. Ensure people living with dementia can live safely in their own homes for as long as possible	Ensure people living with dementia and their families and carers have access to flexible range of technology to meet their needs at different stages of their dementia journey Ensure the right support is in place for people living with dementia and elderly carers to use technology effectively	Ensure people living with dementia, their families and carers have relevant information about technology that can support them at end of life

# 4

## EMERGING AREAS FROM CONSULTATION

### 4.1

## Awareness, prevention, support and end of life care

The formal consultation survey on the strategy was hosted on the Council's consultation webpages for six weeks, between 9 November to 21 December 2022. The survey aimed to capture views on the draft Richmond Health and Care Dementia Strategy. Comments collected through the formal consultation survey informed the development of the final Richmond Health and Care Dementia Strategy and a supporting "You said: We did" paper has been produced.

The key emerging themes were:

#### **More needs to be done to improve dementia awareness and the risk factors for dementia.**

Prevention and awareness still needs to be a long-term, strategic goal for the community as it is not currently deemed a key issue for people with a diagnosis of dementia or their carers. dementia awareness and prevention should be prioritised so that the future population of Richmond can tackle it more effectively.

Advice should be given about how to prevent dementia through everyday activities. This awareness should start from schools and via local communities. The information could be distributed digitally as well as through community workers.

There was a call for GP surgeries to clearly display the signs of dementia so that patients and family can look out for these. They should also provide information on who to contact and where to go for further advice.

**Increase support and psychosocial support options should be made available for carers in Richmond. This should include council provided day centres as well as self-funded support, packages of care through local charities and bespoke activities.**

- Support groups should be created for families of people living with dementia and for carers
- Active support should be provided for those suffering from dementia
- Local community radio or podcasts should be created for information and advice
- Involve other charities to provide additional help,

### Health and Care Integration

- A continued focus on integrating services is needed
- Keeping people out of hospital should be a priority, connect support in the community and continuing care.

### End of life care

Whilst end of life care is included in the dementia strategy, there is a need to make sure that the needs of people living with and affected by dementia, and their carers is covered in the SWL End-of-Life Strategy.

### The post-diagnostic gap provision for YOD patients and carers

Potential actions could be two fold: 1) at Richmond level, consider resourcing a pilot for YOD virtual hub 2) influence the system agenda for a SWL YOD post-diagnostic provision

## 4.2 Scoping a dementia Hub

There was agreement that a telephone line could be the initial plan and long term a building or location could be acquired for a physical dementia hub. If the opportunity arose to provide a physical Dementia Hub this would be great for the community. The consultations and engagement highlighted the following considerations

- This could be a model that could accommodate using a hub and spoke design incorporating a hub with fixed spokes or a mobile unit.
- A hub would need to ensure that the venue had or could provide access to or make access easier to a wide range of services which could support peoples relatively ordinary needs.
- The hub would need to be accessible across the borough.
- A central hub or contact point to locate NHS and statutory sector staff could support relationships between relevant NHS personnel and both the local authority as well as the Voluntary Sector organisations, even if delivery was through community venues.
- Whilst some sort of directory of potentially relevant services could help, it could not be presumed that people would have the capacity to navigate services unsupported. This may be the case for carers as caring can be extremely time intensive and some kind of fixed support points (or personnel) to provide support could help.
- A combination of approaches is likely needed to support service users and ensure joined up approach.
- A hub could be a central point of access to information and services.
- The hub could host a section for those with dementia and their carers re dementia, services and support available. A separate section for carers support and advice.
- Any hub would need to be a central resource. For example a phone line which acts as a central resource providing expertise, help, signposting and direction when required.

**“There remain a lot of gaps/holes in the system. I agree a hub needs to be set up to pull everything together”**

**Shara**

## 4.3 Digital technologies, social isolation and access

Increasing age is a risk factor for social isolation. People aged over 75 have a greater risk social isolation than younger older people. In Richmond 12% of households are pensioners living alone and 48% of social care users aged 65 over years reported having as much social contact as they would like. People affected by dementia and their carers can be at an increased risk of social isolation.

The local environment significantly impacts on the wellbeing of older people. Older people spend more time in their neighbourhood than young people. A recent review suggested that new technologies and community engaged arts might be seen as a promising tool for tackling social isolation and loneliness among the older people. Richmond residents suggested addressing digital exclusion to improve social isolation locally. Reducing digital exclusion is different from digital-technology interventions, the potential remains for technology to act as a 'gateway' to services that may reduce isolation and loneliness.

A realist evaluation on befriending concluded that befriending services should be tailored to the needs of service users and take into consideration specific needs including:

- Mobility
- Physical, sensory and cognitive impairments
- The influence of service characteristics, including payment for befrienders
- Fixed or long-term befriending relationships
- One-to-one support
- The impact of non-verbal communication via face-to-face delivery.

This reflects work in Richmond to increase volunteer confidence in working with people affected by dementia and their carers so that they can carry out befriending.

There is evidence that highlights the challenges to people with cognitive impairments have in accessing services. People with dementia and their families face complex challenges on a day to day basis. These challenges are likely to be practical (e.g. learning how to use technologies), moral (e.g. choosing how and when to curtail a person's freedom), and neurological (e.g. living through altering cognitive capacities).

Research suggests that it is vital to engage with those living with dementia and their carers to prevent social isolation and it's impact on their wellbeing.

**“Service users want clear concise non-ambiguous information. A directory works for some though there's a lot of information in it which can be confusing”**

## 4.4 Supporting Unpaid carers

A person looking after someone who needs support because of an illness or disability and cannot manage without help, can be considered a carer.

The nature of dementia means that a lot of the support offer is for the unpaid carers – family and friends who the person with dementia relies on for support. This is a Crosscutting areas across the pathway. There are a range of services aimed specifically at carers in the borough, for example:

- Information and advice
- Short breaks from caring
- Emotional support and counselling
- Peer support and training
- Digital Inclusion and Technology solutions
- Complementary therapies
- Events and activities
- Carers Assessment

98% of the service users at the Council's specialist day centres at Woodville, Sheen Lane and the Access project in Whitton have unpaid carers.

The voluntary and community sector in Richmond provide an array of services for unpaid carers that are funded by other sources. There are also a range of services funded and/or delivered by the Council, the NHS and community and voluntary sector that carers will access even though they may not be designed explicitly for carers.

Carers of people with dementia also need access to preventative services such as NHS Health Checks, mental wellbeing Support as carers may overlook their own health needs.

Targeted support for paid and unpaid carers and people who have dementia can ensure that they are getting psychological support. Richmond Wellbeing service target carers specifically to increase access to psychological therapies for anxiety or depression as well as sleep problems.

### Adult Social Care Team

There has been a specific focus on carers to:

- Improve and enhance carer education
- Identify and assess the needs of unpaid carers of people with dementia and provide necessary support
- Robust monitoring of the quality-of-service provision for residents with dementia and their carers and embed any learning from complaints and audits
- Maintain good collaborative working relationships and communication across the many services that work together to support residents with dementia and their carers

### “What good looks like”

“My family and friends who care for me are supported to have a life outside of their caring role”

“We want to be accepted by all in the community”

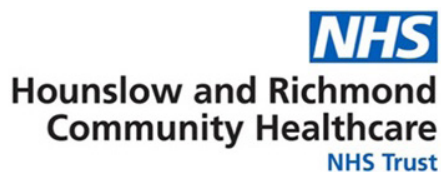
“Richmond is a dementia friendly borough, where people living with dementia and their unpaid carers feel accepted in the community”

Short term, medium term and long term goal for unpaid carers

- **Short term** -- All unpaid carers of people with dementia will have a carer's assessment that is regularly reviewed
- **Medium Term** -- Increased opportunities for short breaks including respite for unpaid carers of people living with dementia
- **Long term** – Unpaid carers of people with dementia will have access to a range of psychological therapies to prevent carer breakdown

# Partnership

Public Health



# Glossary

<b>Admiral Nurses</b>	Specialist dementia nurses.	<b>ICB</b>	Integrated Care Board (a part of the Integrated Care System).
<b>ASC</b>	Adult Social Care Division, London Borough of Richmond upon Thames Council.	<b>JSNA</b>	Joint Strategic Needs Assessment.
<b>AUKR</b>	Age UK Richmond. A local charity working in the community to support older people, their families and carers.	<b>LBRuT</b>	London Borough of Richmond upon Thames.
<b>CCG</b>	Clinical Commissioning Group (ended in July 2022). Replaced by ICB	<b>MAS</b>	Memory Assessment Service.
<b>CHC</b>	NHS continuing healthcare	<b>MECC</b>	Making Every Contact Count training.
<b>CILS</b>	Community Independent Living Service (CILS) is a partnership of 20 local charities, supporting adults of all ages to live independently, improve wellbeing and stay connected with their local community.	<b>MDT</b>	Multidisciplinary Team. This is a group of health and care staff who are members of different organisations and professions (e.g. GPs, social workers, nurses), that work together to make decisions regarding the treatment of individual patients and service users. MDTs are used in both health and care settings.
<b>CMHT</b>	Community Mental Health Trust.	<b>NICE</b>	National Institute for Health and Care Excellence. NICE provide national guidance and advice to improve health and social care.
<b>CQUIN</b>	The Commissioning for Quality and Innovation framework. Supports improvements in the quality of services and creation of new and improved patterns of care (NHS England).	<b>Public Health</b>	Public Health Division, London Borough of Richmond upon Thames Council.
<b>CVD</b>	Cardiovascular disease (CVD) is a general term that describes a disease of the heart or blood vessels. Blood flow to the heart, brain or body can be reduced because of a blood clot (thrombosis).	<b>QOF</b>	Quality and Outcomes Framework - A voluntary annual reward and incentive programme for all GP surgeries in England, detailing practice achievement results and good practice (NHS).
<b>DeAR-GP</b>	Dementia Assessment Referral to a GP.	<b>RAID</b>	Richmond Aid. RAID is a charity that supports people of all ages with all disabilities, including physical and sensory impairments, mental health issues and learning difficulties.
<b>Dementia Friend</b>	A dementia Friend is somebody that learns about dementia so they can help their community.	<b>RUILS</b>	Support disabled children, adults and the elderly to live independent lives by providing information, advice, advocacy, practical support, activities, and befriending.
<b>DFR</b>	Led by AGE UK. This dementia friendly communities initiative aims to create an inclusive borough where people affected by dementia feel supported, included and understood in community life.	<b>SSA</b>	Shared Staffing Agreement. This refers to staff that work in Richmond Council.
<b>DHSC</b>	Department of Health and Social Care.	<b>VCS</b>	Voluntary and Community Sector.
<b>DN</b>	District Nurse.	<b>WTE</b>	Whole Time Equivalent. This is a unit to measure an employed person in a way that makes them comparable although they may work a different number of hours per week.
<b>DPLG</b>	Dementia Pathway Liaison Group	<b>YOD</b>	Young Onset Dementia (YOD) is Dementia which develops in people under the age of 65
<b>EDI</b>	Equality Diversity & Inclusion (EDI) policy ensures fair treatment and opportunity for all		
<b>HRCH</b>	Hounslow and Richmond Community Healthcare.		
<b>IAPT</b>	Improving Access to Psychological Therapies		
<b>ICS</b>	Integrated Care System (replaced CCGs in July 2022). This is a formal partnership that will help to deliver an improvement in care for people.		

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