



# Richmond Health and Care Dementia Strategy

A ten-year strategy 2022-2031



Public Health



# Contents

|   |    |   |    |   |    |  |    |
|---|----|---|----|---|----|--|----|
| <b>Message from Lead Member</b>   | 3  | <b>2 DEVELOPING OUR JOINT HEALTH AND CARE DEMENTIA STRATEGY</b> |    | <b>4 NEW INITIATIVES ACROSS THE PATHWAY</b>                   |    | <b>7 EMERGING EVIDENCE BASE</b>            |    |
| <b>Message from Director of Public Health and from Integrated Care Services Clinical Lead</b> | 4  | <b>2.1</b> How we developed this strategy                       | 16 | <b>4.1</b> Pathway Phase One                                  | 29 | <b>7.1</b> National and local strategies   | 45 |
| <b>Executive summary</b>  | 5  | <b>2.2</b> Principles, approaches and aims for the strategy     | 17 | <b>4.2</b> Pathway Phase Two                                  | 31 | <b>7.2</b> National and local policies     | 46 |
| <b>1 INTRODUCTION</b>   |    | <b>2.3</b> Co-production and engagement processes               | 18 | <b>4.3</b> Pathway Phase Three                                | 34 | <b>7.3</b> Evidence from national research | 47 |
| <b>1.1</b> Dementia   | 6  | <b>2.4</b> Strategic objectives and priorities                  | 19 | <b>4.4</b> Pathway Phase Four                                 | 34 | <b>7.4</b> Evidence from local research    | 48 |
| <b>1.2</b> The vision   | 8  | <b>3 THE DEMENTIA PREVENTION AND CARE PATHWAY</b>               |    | <b>4.5</b> Pathway Phase Five                                 | 37 | <b>7.5</b> JSNA                            | 50 |
| <b>1.3</b> About Richmond   | 9  | <b>3.1</b> Current services and mapping                         | 20 | <b>4.6</b> Dementia Hub                                       | 37 | <b>7.6</b> Key findings                    | 50 |
| <b>1.4</b> Dementia system  | 10 | <b>3.2</b> Gaps and areas for development                       | 28 | <b>4.7</b> Social isolation and Access, Digital technologies  | 39 | <b>7.7</b> New practice from new research  | 51 |
| <b>1.5</b> What we have achieved since the last strategy                                      | 11 |   |    | <b>5 WORKING WITH PAID AND UNPAID CARERS</b>                  | 40 | <b>8 ACTION PLANS</b>                      |    |
| <b>1.6</b> Equality, Diversity and Inclusion (Edi)  | 15 |   |    | <b>6 HOW WE DELIVER DEMENTIA PREVENTION</b>                   |    | GLOSSARY                                   | 53 |
|   |    |   |    | <b>6.1</b> Social Prescribing for people affected by dementia | 42 | BIBLIOGRAPHY                               | 54 |
|   |    |   |    | <b>6.2</b> Reducing health inequalities                       | 44 | ACKNOWLEDGMENTS                            | 55 |

# Message from Lead Member

## 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 social care system can fail to support people affected by dementia.

The Richmond Dementia strategy refresh done in 2019 started to address the gaps and opportunities to improve the dementia offer across Richmond. Building on the strategy and delivering a long term comprehensive dementia prevention, and care support offer for residents affected by and living with dementia remains a key focus for Richmond council alongside partners across the health and social care arena.

Alzheimer's UK 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**

## 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 affect 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**



# Executive summary

Dementia is a complex progressive syndrome involving a group of related symptoms. It is associated with an ongoing decline in brain function and there is currently no cure.

People with dementia have complex problems and symptoms in many areas of life which mean they need help and support to manage their needs. Dementia is a collective term for a group of diseases which include Alzheimer's, vascular dementia and dementia with Lewys bodies.

THE VISION OF  
THE TEN YEAR  
STRATEGY IS:

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

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 as well as the implementation of the Richmond Dementia Strategy.



# 1

## INTRODUCTION

### 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 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, it accounts 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 The 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.

THE VISION OF  
THE TEN YEAR  
STRATEGY IS:

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

Work done by the Richmond Clinical Commissioning Group (CCG) asking what good dementia prevention and care is reveals

### What good looks like for people with Dementia in Richmond

#### '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.

## 1.3 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).



## 1.4 Dementia system

### 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 as well as the implementation of the Richmond Dementia Strategy.

The DPLG continue to meet quarterly and regularly review their delivery and outputs. 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'. All DPLG members felt that it was 'of great value and helps to focus the work'. They all valued the communication and relationships built and recommended that this collaborative working across the dementia pathway should continue.

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 Equality statement, and a dementia prevention and care showcase event held in February 2022. This event highlighted the actions of the Joint Dementia Strategy refresh 2020-2022.

### 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 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.

A report was published in December 2020 (Richmond Dementia Report - Emerging learning and recommendations in the context of COVID-19 across the local dementia prevention and care pathway). The report set out emerging local learning and made recommendations about improvements to meet the changing landscape across prevention, diagnosis, and care of dementia in the context of COVID-19.

### Dementia system-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.

### Dementia System- Southwest 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.

## 1.5

# What we have achieved since the last strategy

## Delivered actions and services across the five dementia

### Priority phases

The pathway comprises:

**Priority phase 1** - Preventing dementia

**Priority phase 2** - Diagnosing dementia

**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

The pathway has been found to still be relevant and necessary, and the dementia pathway underpins the strategy, but the strategy needs to prioritise what is possible and achievable.

The actions under each phase will be explored in the following pages.

Using the concept of “prevention” for dementia can be problematic. It is actually be “reducing risk” as we still know how to prevent Alzheimer’s, because we are not sure of the cause.

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.

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).

### Positive Dementia Conferences led by HRCH

- The aim of the conference in September 2022  
**Dementia is everyone’s business**
- To raise awareness of local positive dementia care initiatives
- To encourage positive dementia care in all interactions with people living with dementia and their carers
- To raise awareness of national initiatives



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).

## **PRIORITY PHASE 1. Preventing Dementia subgroup**

This work is led by Public Health and Adult Social Care Commissioners.

- 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 which also included details 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 MECC module. This module was accessed and completed by 35 people, with 23 people having completed the Dementia MECC module in 2021-22.
- The Dementia Friendly Richmond (DFR) contract, provided by Age UK Richmond, has completed its first year. Key achievements include sign up from 54 local organisations, with all of them having submitted their action plans. 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.
- 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.
- A public awareness campaign 'Think Brain Health' to raise awareness of risk reduction/prevention and lifestyle messaging for dementia prevention.

## **Dementia Friendly Communities Richmond**

- The Dementia Friendly Communities Richmond (DFR) initiative re-launched in April 2021 picking up the work that was completed in 2017 when there were 99 members of the Richmond Dementia Action Alliance. DFR objective was to develop communities that are dementia friendly to help strengthen the resiliency of unpaid carers.
- 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. By creating more accessible services for people living with dementia, it reduces the isolation that many carers experience if they are unable to attend settings and activities that they used to attend prior to their loved ones diagnosis. Dementia Friendly Communities can also increase the likelihood that unpaid carers will be able to find the information they need to help them care for their loved one whilst also having a life outside their caring role.
- Almost 100 Action Points have been achieved since then and there are 62 members of the group.
- There are over 136 Dementia Friends now in place.
- The DFCR coordinator is now a member of Richmond Chamber of Commerce which will enable them to meet face-to-face with local businesses and encourage them to join us in our aim to make Richmond more dementia friendly.
- In 2022 Dementia Awareness Week held a Dementia Information Day at Elleray Hall (a member of DFCR) 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 DFCR 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.



## 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 Southwest London and St George's Mental Health Trust and the Senior Transformation Manager South West London Clinical Commissioning Group.

- The NHS and local clinicians work closely with the Memory Assessment Service (MAS) and work 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 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.

## PRIORITY PHASE 4.

### Living well and enabling a fulfilling life group.

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 contract was awarded to deliver one-to-one counselling to 25+ unpaid carers at risk of carer breakdown. This ended in March 2022 and is currently being reviewed.
- 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.
- We are delivering a multiagency and partnership approach to dementia care and support in Richmond.
- 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.
- A successful survey of the understanding of dementia awareness and lifestyle risk factors among Council staff. Has taken place.
- Dementia Friendly Richmond has been established.
- 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

## Emerging Areas

### 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.

- GP surgeries should 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.
- 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.

### 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 dementia sufferers 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

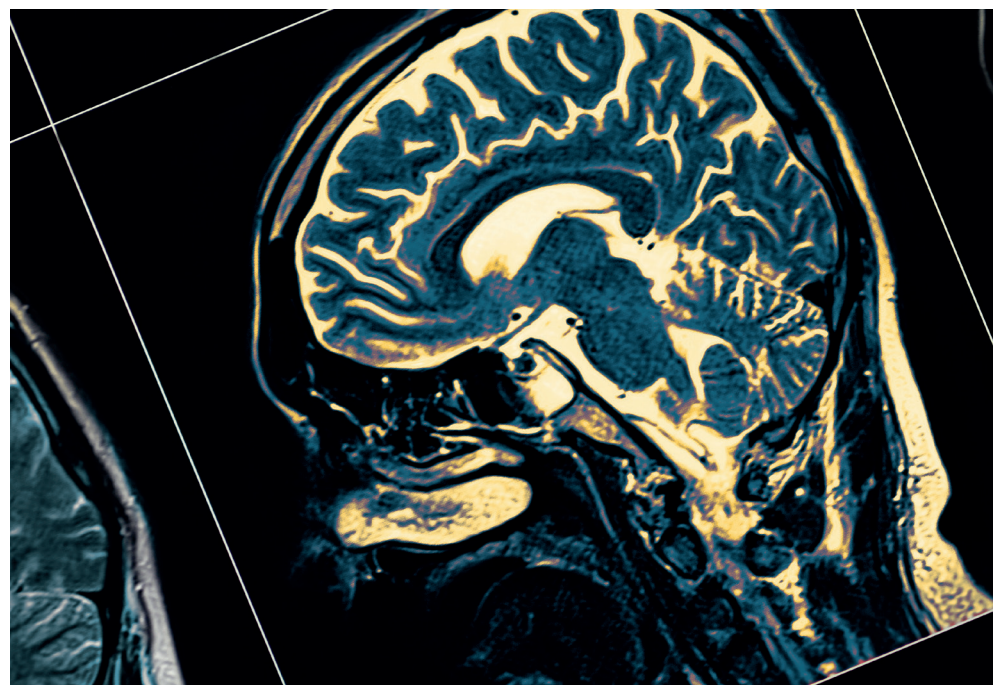
- A continued focus on integrating services is needed.
- Keeping people out of hospital should be a priority, connect support in the community and continuing care.

"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



## 1.6

# EQUALITY, DIVERSITY AND INCLUSION (EDI)

### Equality Diversity and Inclusion (EDI) Position statement

Ensuring equality, diverse 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.

### Family of choice

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.

### 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.

There is work across the Council to ensure that the needs of unpaid carers including those



supporting the diverse community are met including 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.



# 2

## DEVELOPING OUR JOINT DEMENTIA HEALTH AND CARE STRATEGY

### 2.1

## How we developed this strategy

Following the conclusion of the refreshed the 2019-2021 strategy that delivered the Dementia Care and Prevention Pathway, Richmond Council and health partners are currently developing a new dementia strategy.

The dementia pathway identified need for action to collaboratively improve awareness of dementia and improve access to, and quality of dementia services in the borough in the refreshed strategy have been found to be a cornerstone framework for successful delivery. Work to develop the next joint Dementia Health & Care Strategy began with a dementia prevention and care showcase event in February 2022. This raised awareness of the dementia prevention and care services to the relevant target audiences and provided an opportunity for new learning, sharing good practice, networking, and future planning.

#### The key findings for strategy development were:

- There is a need to demonstrate a holistic approach to increase knowledge and understanding of what is needed.
- There was a strong steer for support for a dementia hub being in the community.
- Robust emphasis on how to further support unpaid carers is required.
- There was clear emphasis on the need to understand how to support people without paid carers.
- Engaging with those with lived experience and facilitating their voice is vital.
- Reaching underserved communities.

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

**Maria**

## 2.2

# Principles, approaches and aims for the strategy

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 | ■ Empowering                              |
| ■ Partnership working     | ■ Prioritise what is possible/achievable. |
| ■ Evidence based          | ■ Equality, Diversity and Inclusive       |
| ■ Prevention focused      | ■ Access to universal services.           |



## 2.3

# 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.

## 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.

## 2.4

# Strategic objectives and priorities

### Objectives

#### Short term - Two years

- 1** To audit the dementia training available, identify and ensure it meets identified need.
- 2** To have increased awareness of dementia within the community and the support available to people with dementia and their carers by the end of two years.
- 3** In the first two years to ensure that all people living with dementia and their carers have access to universal healthy lifestyle services.
- 4** By the end of year two of the strategy people can access their support and care in a seamless manner
- 5** In the first two years we will upskill voluntary organisations, volunteers, community health champions and other community partners so they feel confident to work with people with dementia and their carers and have meaningful contact .
- 6** By the end of the first two years all Richmond GP practices will achieve the national dementia target for earlier diagnosis and reduce the gap between those diagnosed with dementia and people undiagnosed, but living with dementia.
- 7** By 2025 all people with a dementia diagnosis will have a co-produced urgent care plans within a year of their diagnosis
- 8** To have increased diagnosis of people living with dementia in care homes who are undiagnosed.
- 9** To increase the number of community dementia nurses and team by two WTE equivalent staff.
- 10** Ensure that the South West London End of Life Strategy has a focus on people living with dementia and their carers.
- 11** To have clear plans in place for Dementia hub co produced with stakeholders

#### Medium term - Five years

- 1** By the end of five years to have incorporated key strands from the national strategy.
- 2** To have a range of digital and non-digital tools to support people with routine daily tasks.
- 3** To have overseen a smooth transition from hospital care to health and social care.
- 4** To have all council owned and commissioned leisure centres dementia friendly in the first five years.

#### Long term - 10 years

- 1** To have a decreasing trend in rates of vascular dementia in Richmond
- 2** Richmond is a dementia friendly borough, with more people with dementia dying at home or in their usual place of residence with dignity, than in hospital.

### Points of focus

Taking a collaboration and a co production approach, a set of key points of focus have been constructed within the dementia prevention and care pathway. Under each priority phase , some action points are described according to the five points of focus of:

- 1** Improving dementia awareness
- 2** Improving access to equitably distributed dementia-related services and
- 3** Improving quality of local dementia-related services
- 4** Ensure a smooth interface and navigation between dementia services for people affected by dementia, carers and those who work with them
- 5** Develop a digital offer that provides accessible and easy to use offers



# 3

## THE DEMENTIA PREVENTION AND CARE PATHWAY

### 3.1

## Current services and mapping

### **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 have been providing excellent information, advice, and signposting at the front door, including to NHS and voluntary sector services, including benefits and money management advice. Co-production to ensure a range of practical solutions and psychosocial interventions are readily available. 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 lead service providing support to GPs for patients with Dementia in the community. They bridge the gap between our secondary care dementia services and the GPs. They provide a professional confidential service to support both patient and carer to live well with dementia. They would respond to a GP referral within 48 hours to start their assessment process. They aim of providing an appointment for a home visit within five days of receiving a referral and would assess the patient and carers needs.

### **Crossroads Care:**

As part of the Richmond Carers Hub, Crossroads Care is contracted to run a twice monthly Caring Café. Furthermore, as part of the Richmond Carers Hub, Homelink run a support group for unpaid carers of people with dementia. Homelink also offer a Carer Support Service that is not funded by the Council that offers emotional support and peer activities.



### **Dementia Friendly Richmond (DFR):**

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 LBRuT a more dementia friendly borough. Funded by the Council and lead by Age UK Richmond (AUKR), 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.

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.

### **Dementia Adviser in Barnes:**

The adviser works within the Memory clinic five days a week. This is subcontracted by the CCG to SW 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.

The Dementia Services Directory can be viewed here:

[www.richmond.gov.uk/media/20317/richmond\\_dementia\\_support\\_directory.pdf](http://www.richmond.gov.uk/media/20317/richmond_dementia_support_directory.pdf)

### **Richmond Carers Hub Service:**

The Richmond Carers Hub Service is a group of local organisations commissioned by London Borough of Richmond upon Thames and NHS to provide between them, services specifically for carers in the borough. Richmond Carers Hub, includes over 420 carers of people with dementia.

### **SWLSTG Mental Health Trust Dementia Services:**

Under this service there are specialist services and interventions for people with Dementia.

Richmond Memory Assessment Service:

The memory service is for people in Richmond presenting with symptoms of mild to moderate dementia who have not already received a diagnosis. GP will refer their patients to MAS who be displaying memory problem and they suspect it may be the sign of a mild to moderate dementia which is beginning to impact on the person's day-to-day functioning.

### **Woodville Day Centre:**

Woodville Centre is a council run specialist day centre for adults aged 60 plus 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 individuals 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 to engage with the young person with Dementia and their family within the Borough of Richmond through one to one support and provision of advice and information. They raise awareness of Young Onset Dementia across borough, and wider health services and other organisations.

## **Hounslow and Richmond Community Health care services (HRCH) Community Dementia Service**

The Richmond Community Dementia Service was originally created following a CQUINN with Richmond CCG in September 2015 to support patients registered with a Richmond GP Practice.

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 they 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. The service has several components:

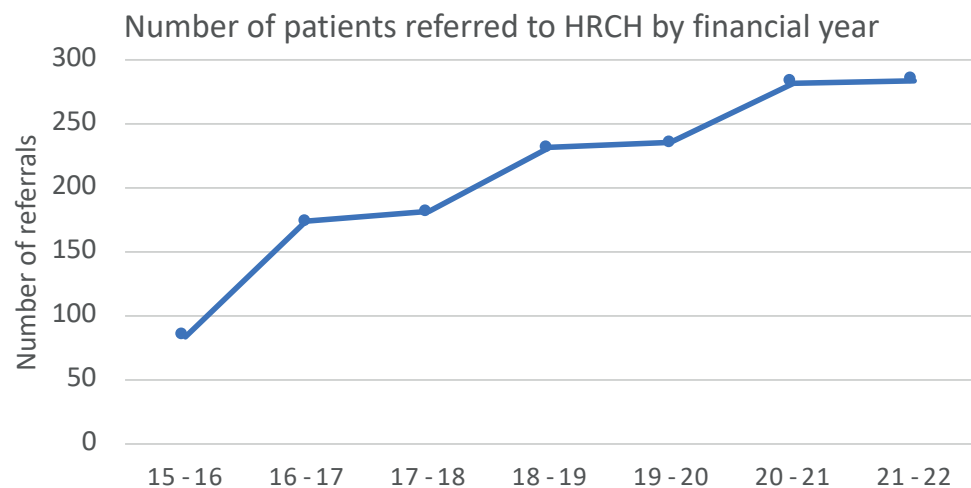
- Patient caseload
- Supporting carers
- Teaching staff
- Working within HRCH to promote dementia care within all services and to encourage dementia friendly clinical environments.
- Networking and liaising with external stakeholders and the wider health service

Since its creation in 2015, the service has seen an ever-increasing referral rate as shown in the chart. This increased dramatically during the Covid 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 an average 23 referrals per month, so far for 2022-23 it is averaging at 20 referrals per month.

The number of patient contacts have increased dramatically during the Covid pandemic to an average of over 90 contacts per clinician per month and have not returned to pre Covid levels

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.



## 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](mailto: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.

[www.alzheimers.gov/clinical-trials/search?searchTrial](http://www.alzheimers.gov/clinical-trials/search?searchTrial)

### Dementia Awareness

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

GPs and community pharmacies as they 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 centred care.

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** – Richmond Public Health 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

## 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

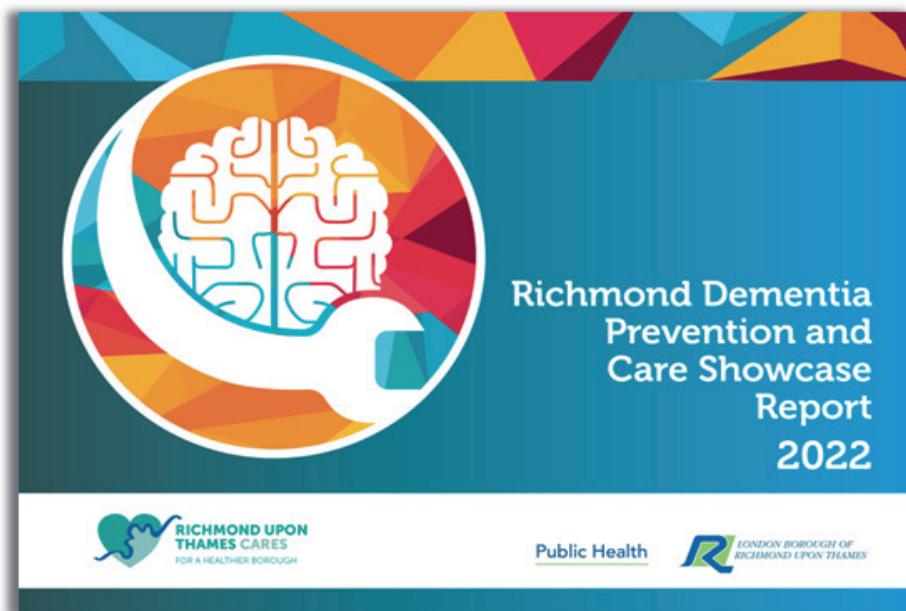
Pharmacological: Medications may be prescribed and once a person's condition is stable MAS discharges to GP. If behavioural and psychological symptoms develop, GP may refer to Hounslow and Richmond Community Hospital(HRCH) community dementia service or back to the Community Mental Health Team (CMHT) 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.



The general post-diagnostic support pathway for people with dementia is that they will be diagnosed by a specialist – usually a memory assessment service – who may also provide immediate support after diagnosis.

After some time, 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.

## 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.

## Ensuring dignity and comfort: End of Life

A person at end of life (EOL) may have expressed wishes about end of life care. Such wishes may appear in a written document such as the Urgent Care Plan or a future planning document. If there is no EOL plan a suitable family member of choice should be involved in decisions and kept up to date at all times.

**Palliative care teams:** In the hospital or community these teams give advice and information on living with a terminal illness and managing any symptoms. Palliative care teams and local district nurses organise end of life care according to the person's wishes, at home, in a care home, hospice or in a hospital. Adult Social Care teams can provide home adjustments as required.

**Hospitals:** Patients with end of life (EOL) wishes should share their plan with the hospital staff. Patients can be referred to Kingston Hospital's EOL team and/ or Dementia & Delirium team if admitted to hospital. Any EOL plans made in the hospital setting should with be communicated with the patient's GP and other services as appropriate.

After a death, the care team or GP will support family members with information on what happens after a death and signposting to bereavement services as appropriate.

## Young Onset Dementia (YOD)

People aged under 65yrs 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 at 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.

## Defining Young Onset Dementia

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. The Young Dementia Network is a movement of people committed to improving the lives of those affected by young onset dementia. People with dementia whose symptoms started before they were 65 are often described as 'younger people with dementia' or as having young-onset dementia.

The 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 Oct to Nov 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 very 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 group for the YOD population in Richmond.

- 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 change to dementia connect providing more 1:1 support and moving away from group work.
- This population need age appropriate support. YOD Peer navigator – Focus on developing pathways to access services?

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

## 3.2 Gaps and areas for development

### New actions needed include:

#### Social care

- Increased availability of social care and the help people need with everyday tasks such as washing, dressing and shopping for essentials.
- Adult Social Care to better to support residents with one off grants for digital tech which will help them live independently.
- More Social services involvement and increased case finding.
- Discussion about developing a local screening – what families can do if they or individual notice cognitive decline.
- Current lack of coordination by social care needs visible quality improvement targets.

#### Support for carers

- Co-production is needed to ensure a range of practical solutions and psychosocial interventions are readily available.
- The care pathway from 1st diagnosis to end of life, should be tighter and smoother for the person and their carer and ensure that there is support throughout the journey.
- Further develop social prescribing for dementia sufferers and carers.

#### Reaching hard-to-reach communities

- Identify underserved communities in the communities and care home
- There is a need to do more for hard-to-reach communities in any future dementia prevention campaigning as well as promoting support offers
- Look at population backgrounds/data in different wards in the referrals made from memory clinics and GP referrals. To identify if any populations are under represented or missing
- Increased Communication campaigns and dementia awareness training
- Maintaining the current level of Dementia Friend partners means the current project is at full capacity.
- One of the biggest challenges has always been to find a 'care coordinator' as recommended in the NICE guidelines this would solve a lot of issues in Richmond around multiple providers involved in a person's life and will need to be considered as part of developing hub arrangements



# 4

## NEW INITIATIVES ACROSS THE PATHWAY

### 4.1

## PATHWAY PHASE 1 Preventing dementia

Dementia Awareness and Prevention will be prioritised so that the future population of LBRUT can tackle it more efficiently.

More than one third of cases of dementia are potentially avoidable through modifiable lifestyle factors. Changes in mid-life can have the most 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 amenable to prevention. 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% (95% CI 2.4% - 17.6%) of cases of dementia in Richmond are attributable to physical inactivity and 4.9% (95% CI: 1.3% - 9.3%) of cases 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', provided recommendations to support in delaying 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 the schools 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.

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 reduced risk of dementia. Cognitive stimulation therapy (CST) is a brief treatment for people with mild to moderate dementia involves taking part in group activities and exercises designed to improve memory and problem-solving skills.

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.

### 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.

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

### Preventative actions

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 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. 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 - '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.

### Dementia Awareness Training

Dementia awareness training is mandatory for primary care staff (GPs/pharmacies) that deliver the NHS Health Checks service. 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.

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.

#### 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. 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 results, recommendations and next steps following the DAM1 were:

- The DAM1 was undertaken by 8% (328) of the SSA workforce. Participation was not equally distributed among all Directorates within the SSA (Figure 1). Minority ethnic groups were underrepresented.
- The most common reasons for delaying 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.

### Think Brain Health Campaign

The 'think brain health' social media campaign launched in June 2022 is to support increased awareness on dementia risk reduction to increase motivation for people to engage in relevant protective health behaviours. To further support this, there are plans to deliver a series of informal conversations amongst residents and community groups to increase awareness on dementia risk reduction so focusing on physical exercise, alcohol, smoking, diet, staying socially and mentally active and hearing loss.

### Future Plans

The findings from the DAM1 will be used to develop and strengthen Dementia Awareness Training, with emphasis on improving understanding of these areas where knowledge was shown to be lower and a series of shorter trainings focusing on a specific area such as risk or prevention could also be developed alongside the core training and we will measure changes in knowledge and awareness among the SSA over time. and to measure public awareness.

## 4.2

# PATHWAY PHASE 2

## Diagnosing dementia

Timely diagnosis of dementia is important as this allows the person with dementia to be actively involved in decisions about their future life and care, and facilitates access to medical, psychosocial interventions that may improve their condition or situation.

The most recent Memory Clinic Audit by the Royal College of Psychiatrists found huge variation in waiting times from GP referral to diagnosis. The range of time between referral and diagnosis varied from three to 34 weeks, meaning that many people wait over six months to receive a diagnosis. [www.england.nhs.uk/london/wpcontent/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf](http://www.england.nhs.uk/london/wpcontent/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf)

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 specialise in the diagnosis and initial management of dementia.

The memory service accepts referrals from Richmond GPs, geriatricians, neurologists and hospitals, and includes residents of care homes and nursing homes from the Richmond 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 might be arranged before 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.

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 an individual 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). 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.

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.

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.

### 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**

## Supporting Carers

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 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 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.

According to 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.

## Diagnosing Well

- Carers of people living dementia are offered information and support relevant to their needs, throughout their experience with dementia.
- 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.

## Diagnosing Dementia Impact Plan

| Our Goals  | What we will do   | Impact Statement  |
|--|---|---|
| We aim to improve the dementia diagnosis rate in Richmond to meet the benchmarking standard (66.7%) and the SWL ICB standard (70%) and to maintain the standard. | <p>Increase awareness of the early signs of dementia through training in nursing home, residential care, health care and voluntary care settings.</p> <ul style="list-style-type: none"> <li>• HRCH Dementia Nurses and Admiral Nurses will work together on prevention, early diagnosis and pre and post dementia support for families.</li> <li>• Continue to work with GP Practices on QoF registration and coding of new patients.</li> </ul> | <p>Richmond Borough will maintain benchmarking Dementia standards.</p> <ul style="list-style-type: none"> <li>• People will receive timely diagnosis.</li> <li>• Dementia friendly environment.</li> <li>• GP Practices Diagnosis rate will increase through early detection.</li> <li>• The person and their family will receive pre and post diagnostic support.</li> <li>• A more accurate account for people with dementia locally</li> </ul> |
| To offer all those referred for a memory assessment pre-diagnostic support information and post diagnosis support.   | <p>The person and their family will receive information pack on dementia prevention and support.</p> <ul style="list-style-type: none"> <li>• Dementia Directory to be given at the point of a confirm diagnosis.</li> <li>• Referral to a dementia advisor to walk the person and their carer through the process and who to access help when required.</li> </ul>   | <p>The person and their family will feel supported and held by the system during the process.</p> <ul style="list-style-type: none"> <li>• The will feel empowered to care for the family member.</li> <li>• The person and the carer will know who to contact should they need support.</li> <li>• Carers will receive a care act assessment yearly.</li> </ul>  |
| Timely accurate diagnosis, care plan, and review within first year   | <p>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.</p>  | <p>NICE standard access to care to be expected.</p> <ul style="list-style-type: none"> <li>• Each person with dementia to have a care plan detailing their treatment options.</li> <li>• Each person would be seen within 6 weeks for an initial assessment.</li> </ul> <p>The person and family will have access to PHB to plan and arranged the support they need to keep the person at home.</p>   |
| To offer all individuals diagnosed with dementia access to support services which are personalised to their individual needs.                                    | <p>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.</p>   |   |

## 4.3

# PATHWAY PHASE 3

## Supporting after 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.

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.

## 4.4

# PATHWAY PHASE 4

## Supporting after diagnosis - the five year plan

**Our plans to support those living with dementia and their carers are diagnosis:**

- Within the next two years Admiral nurses will work alongside HRCH dementia nurses to provide early prevention, timely diagnosis, training for staff and support for carers.
- We will produce well defined dementia pathway from prevention to end of life care.
- All people with dementia will receive timely support to reduce the risk and manage crisis.
- 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.
- 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.



## 4.4

# PATHWAY PHASE 4

## Enabling a fulfilling life with dementia

The 2019 Dementia Strategy Refresh identified many key areas including people's need to:

**"I live in an enabling and supportive environment where I feel valued and understood. I have a sense of belonging and of being a valued part of family, community and civic life"**

Reducing isolation is the responsibility of all of us whether we are actively working for an organisation that provides opportunities for social interaction or whether are simply checking up on a neighbour.

### 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.

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

These are:

- 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**

## Dementia Friendly Communities Richmond (DFCR)

DFCR 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 Week in May 2021.

Dementia Friendly Communities 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 DFCR 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.

DRF 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 at full capacity.

## 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.



## 4.5

### PATHWAY PHASE 5

#### Ensuring dignity and comfort for those dying with dementia

##### Urgent care plans

- Advanced care planning Continuing care assessments, hospice & DN referrals
- South West London End of life strategy

**"In my experience, many people with dementia and/or their carers do not discuss end of life issues or make their wishes known in a less formal approach.**

**This can be a very distressing issue for carers, when the individual with dementia is beyond the stage of making decisions or letting people know of their wishes"**

## 4.6

### Dementia Hub

If the opportunity arose to provide a physical Dementia Hub this would be great for the community. The following will need to be considered:

- 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.
- A telephone line could be the initial plan and long term a building or location could be acquired for a physical dementia hub.

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

**Shara**

## Evidence from Merton Dementia Hub

Merton Dementia Hub, based in Mitcham is a community-based service for people with dementia, their families and carers.

People can access different health and social care professionals and third sector organisations under one roof.

### Services that have been provided at the Dementia Hub:

- Memory clinic
- Carers' information and support programme (CrISP)
- Support groups for individuals post diagnosis
- Support groups for people with dementia
- Support groups for carers - daytime and evenings
- Therapeutic services (e.g. massage, podiatry and dentistry)
- Weekly Hub Cafés on Tuesday mornings and afternoons
- South Asian Community Café

### Support is also provided in a range of locations across the Borough utilising existing community hubs and spaces, include:

- Dementia adviser service
- Dementia support workers
- Information services
- Blue Sky Café in Raynes Park – first Saturday of every month
- Rainbow Café in Colliers Wood – fourth Friday of every month
- Sunshine Café in Pollards Hill – second Friday of every month
- Singing for the Brain (Raynes Park)
- Newsletter - email and print



### Positive outcomes include:

- Joined up approach to the development of services
- Diagnosis rates have increased from 36% to 53.52%
- Improved access to dementia support services
- Demonstrates value for money - the annual £298.5k cost (as of 2015) has so far reached 600 people

**NB.** This review was done in 2020 prior to the COVID 109 pandemic and it has not been revisited

## 4.7

# Social isolation and Access, Digital technologies

Increasing age is a risk factor for social isolation. People aged over 75 have a greater risk of 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 its 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"**

# 5

## WORKING WITH PAID AND UNPAID CARERS

### 5.1

#### Working with paid and 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. 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.



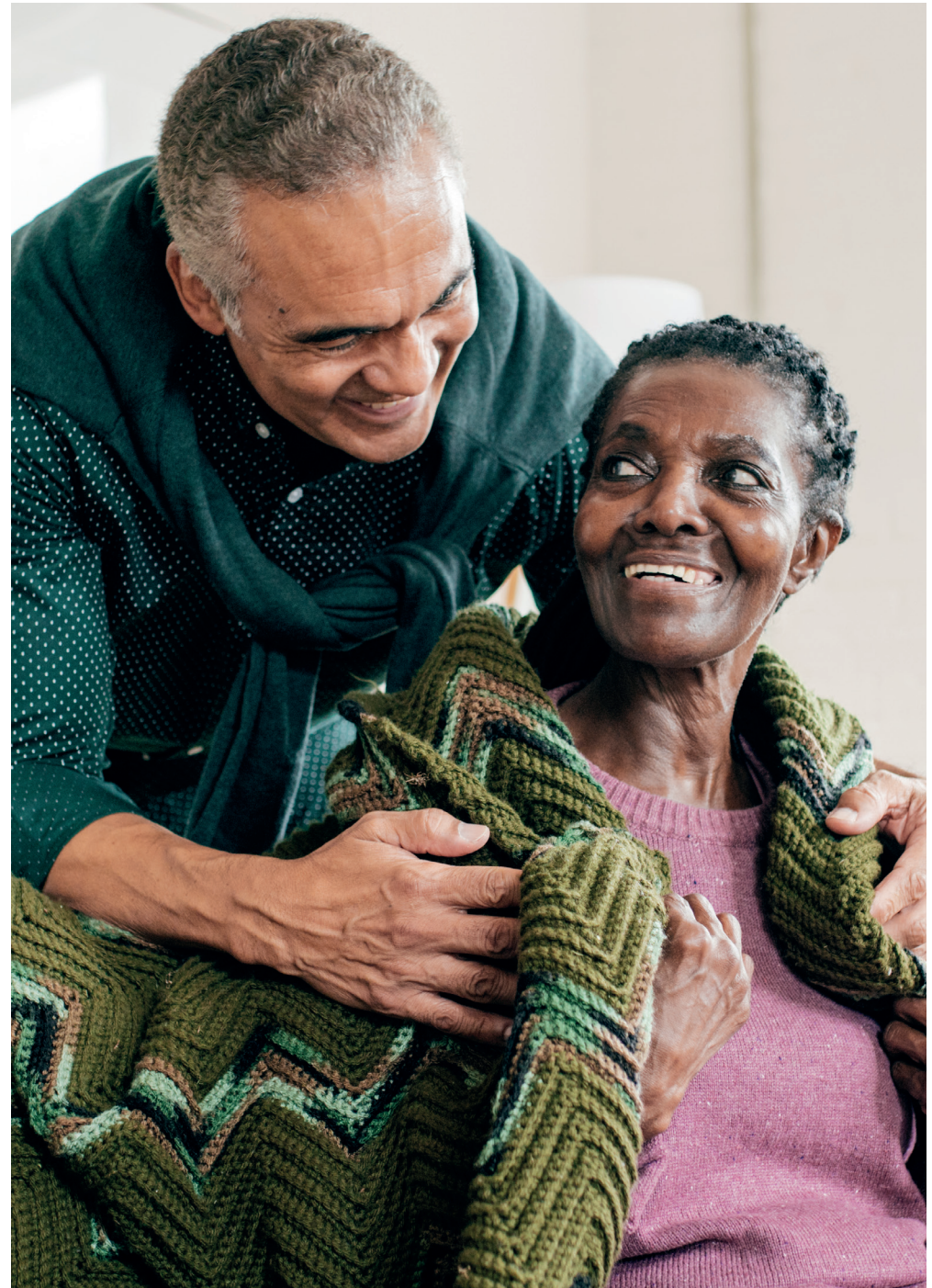
## Preventative actions

The Making Every Contact Count (MECC) module - Recognising and Supporting People Providing Unpaid Care was developed in 2021. 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.

## Adult Social Care Team

There has been a specific focus on carers

- 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





# 6

## HOW WE DELIVER DEMENTIA PREVENTION AND CARE IN RICHMOND

### 6.1 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.

## 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 find out what she was worried about when she went out.
- Researched what was available locally that Suzie could attend by her self 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 Barnes Hospital and Alzheimers' society to join support groups

**ruils**  
Independent Living

### What Social Prescribers Did

- Suzie and Charles were successful in their application for Attendance Allowance
- Suzie was supported on short walks with a volunteer and began walking around the park with Charles again.
- Suzie discovered her long lost passion for art and was able to express her self through this
- Charles got a lot of information from the Alzheimers Website and the support groups
- Suzie and Charles got an Alexa from the council to help remind them of appointments and Suzie used it when she was cooking.

**ruils**  
Independent Living

### Case Study 2

- Grace and George are both in their early 60's and have recently retired from their 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 Alzheimer's type dementia
- Barnes Hospital referred to the Alzheimer's society for support

**ruils**  
Independent Living

### Case Study 2.

- 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

**ruils**  
Independent Living

### What Social Prescribers 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 both George and Grace.
- A referral was made to Age UK to look at Lasting Power of Attorney for both of them and to check situation about their will
- Grace was referred to Carers Centre for additional support and work out strategies for Grace to manage her frustration
- George enjoyed playing bowls and gardening and was referred to Ruils Bowling and Ruils allotment

**ruils**  
Independent Living

### What Social Prescribers did.

- Referral was made to a well-being project for Grace to attend for 6 weeks
- Discussion with GP about George's low mood and prescription of low dose of 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 give them a sense of independence
- They felt that they were in more control of their lives going forward

**ruils**  
Independent Living

## 6.2 Reducing Health Inequalities

### Challenges identified in relation to protected characteristics and dementia

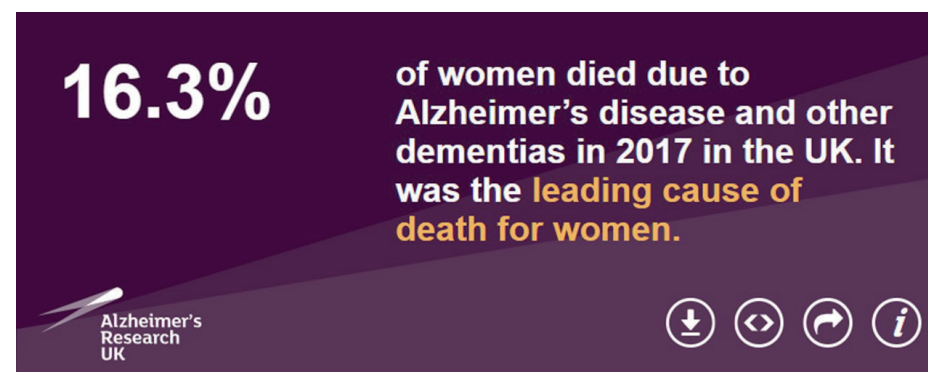
- Ensuring adequate identification of dementia among ethnic minorities
- Providing support for family members of people with dementia who may not be the primary carer.
- Understanding the carers perspective.
- Ensuring flexibility in the carers offer including use of local resources, direct payments 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.

### Understanding dementia risk in black and Asian communities

- South Asians seem to develop dementia – particularly vascular dementia – more often than white Europeans.
- South Asians 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.

### 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 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.



# 7

## EMERGING EVIDENCE BASE

### 7.1

## National and local policies

### 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):

Appropriately resourced

Partnership working

Evidence based

Prevention focused

Empowering

Prioritise what is possible/achievable.

Equality, Diversity and Inclusive

Access to universal services



## 7.2 National and local strategies

### 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:

- 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

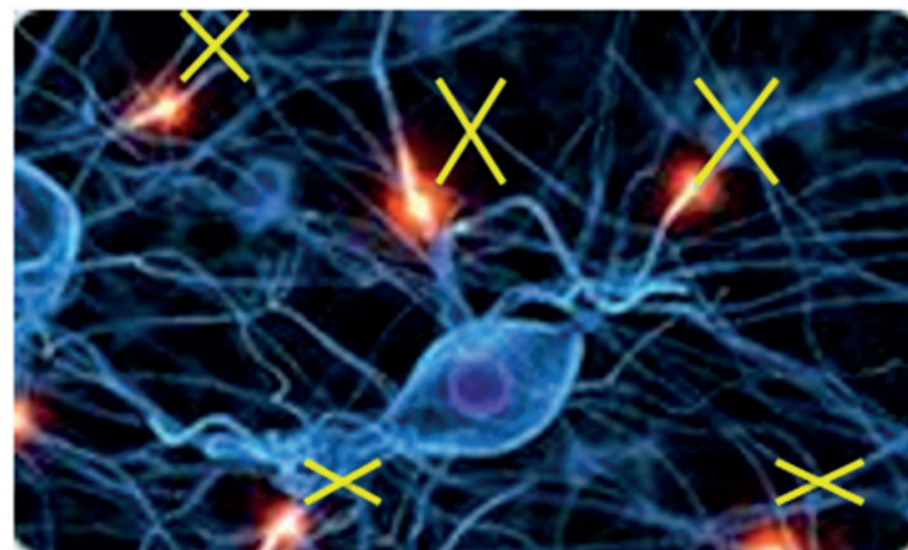
- Memory services spotlight audit
- Appropriate prescribing
- Audiology and memory tool- screening in audiology clinics and screening for hearing
- Prison – older people
- Awaiting publication

### 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





## 7.3

# Evidence from national research

Evidence from research has helped shape work across the dementia pathway and the development of this strategy. Some of the key research used 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 UK, (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.

# 7.4 Evidence from local research

## 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.

## Audit of referrals to Richmond CMHT 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 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/NOK and information about other agencies involved
- The audit concluded that Integration or co-location of a social worker in Richmond CMHT-Older People to reduce delays and improve coordinated approach/reduce risk of complications and crisis in dementia sufferers.
- Need for more robust post-diagnostic pathway, including information dissemination, coordination of services, gaps in evidence-based therapeutic interventions e.g Cognitive Stimulation Therapy.

## Dementia Awareness Measure survey findings

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 is to measure current knowledge and awareness of dementia among the council staff.

The DAM1 consists of 25 questions, which are grouped into themes: risk factors, risk reduction, signs and symptoms, and questions to gather information about DAM1 responders; demographic information and SSA employment data. The DAM1 was undertaken by 8% (328) of the SSA workforce. The report highlights that participation was not equally distributed among all Directorates within the SSA and minority ethnic groups were under-represented.

The most common reasons for delaying diagnosis were:

- difficulty in making a GP appointment.
- worry about what 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. There was variation in knowledge between the different Directorates and within specific ethnic groups. Responses to the open comments question were often very personal and highlighted the importance of dementia care and awareness raising.

## Summary of recommendations:

Consideration should be given to developing a DAM2 to measure changes in knowledge and awareness among the SSA over time.

The DAM 2 could be adapted for wider participation beyond the SSA. This could include healthcare staff working within the local health and social care system and carers.

The findings from the DAM1 should be used to develop and strengthen Dementia Awareness Training, with emphasis on improving understanding of these areas where knowledge was shown to be lower and a series of shorter trainings focusing on a specific area such as risk or prevention could also be developed alongside the core training.

Brief 'did you know?' articles could be developed, to highlight some of the key findings from the DAM1. These could be issued according to theme, for example, symptoms, risk and protective factors, and shared via The Loop.

## 7.5 Joint Strategic Needs Assessment JSNA

This dementia strategy is underpinned by the 2019 Richmond Dementia Health Needs Assessment and intelligence from the 2021 Joint Strategic Needs Assessment. They provided a common view of health and care needs for local dementia residents and their carers as well as identifying current service provision, gaps in health and care services, unmet needs, and evidence of effectiveness for different health and care interventions. Other important resources that have been used to compile the JSNA, alongside additional background information, data, and intelligence, include use of the following:

- Public Health Outcomes Framework (PHOF), Public Health England (PHE) data and analysis tools, Quality and Outcomes Framework (QOF), Projecting Adult Needs and Service Information (PANSI), Projecting Older People Population Information (POPPI), NHS Digital, Office for National Statistics, NHS England Statistics, Richmond Joint Dementia Strategy and DataRich.

This JSNA links closely to other JSNA chapters including those on social isolation and loneliness, End of Life care, and healthy aging (Falls and Frailty). The key themes highlighted in this JSNA focus on the preventing dementia, diagnosing dementia, supporting after a diagnosis, living well with dementia, and dying with dignity.

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%.

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%).

## 7.6 Key findings- Adults and older people's mental health needs assessment, 2022

### Stakeholder feedback:

- There is increasing complexity of mental health needs but a lack of services to manage them.
- 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 service. 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

- The needs assessment recommendations included Improve access to psychosocial support for the family and carers of people with dementia including bereavement and talking therapy services.



## 7.7

# New practice from new research

### Review of evidence based for new practice from new research

The Alzheimer's Society has produced several recent reports under the banner: 'Worst hit – Dementia during coronavirus'

Alzheimer's Society's three reports published in 2021, on dementia diagnosis identify and address the challenges faced by people accessing a dementia diagnosis. These are:

- Ethnic minority communities: Increasing access to a dementia diagnosis
- Regional variation: Increasing access to a dementia diagnosis
- Hospitals and care homes: Increasing access to a dementia diagnosis

There is new practice-based research being undertaken as part of the ESRC-NIHR MODEM project [www.modem-dementia.org.uk/margaret-dangoor](http://www.modem-dementia.org.uk/margaret-dangoor) and at the PSSRU (Kent) and Care Policy & Evaluation Centre (LSE)





# 8

## ACTION PLANS and MONITORING

### 8.1 Governance

The Joint Dementia Strategy accountability is to the Richmond Health and Wellbeing Board and will provide annual progress reports to the Board.

There will be defined and measurable actions to facilitate progress. Once the action plan is ratified, the DPLG group 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 and how the strategy and action plans are resourced.

Oversight of the actions will also be done by the Richmond Place based Partnership.

# GLOSSARY

| Name                                    | Description   |
|---|---|
| Admiral nurses                          | Specialist dementia nurses  |
| ASC                                     | Adult Social Care Division, London Borough of Richmond upon Thames Council  |
| AUKR                                    | Age UK Richmond   |
| Care Plan                               | An agreement for care made between the person with dementia, their family and carers and health professionals involved in their care.   |
| CCG                                     | Clinical Commissioning Group (ended in July 2022)   |
| Cognitive Behaviour Therapy             | A talking therapy that can help someone manage their problems by changing the way they think and behave.  |
| CQUINN                                  | 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)            |
| DeAR-GP                                 | Dementia Assessment Referral to a GP  |
| Dementia Friend                         | A Dementia Friend is somebody that learns about dementia so they can help their community.  |
| Dementia Friendly Communities Richmond  | Led by AGE UK - this initiative aims to create an inclusive borough where people affected by dementia feel supported, included and understood in community life                     |
| DFCR                                    | Dementia Friendly Communities Richmond  |
| DPLG                                    | Dementia Pathway Prevention and Care Group  |
| Equality, Diversity and Inclusion (EDI) | Equality Diversity & Inclusion policy ensures fair treatment and opportunity for all  |
| HRCH                                    | Hounslow and Richmond Community Healthcare  |
| ICB                                     | Integrated Care Board (a part of the Integrated Care System)  |
| ICS                                     | Integrated Care System (replaced CCGs in July 2022)   |
| JSNA                                    | Joint Strategic Needs Assessment  |
| LBRuT                                   | London Borough of Richmond upon Thames  |
| MAS                                     | Memory Assessment Service   |
| MECC                                    | Making Every Contact Count training   |
| Public Health                           | Public Health Division, London Borough of Richmond upon Thames Council  |
| QOF                                     | 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) |
| VCS                                     | Voluntary and Community Sector  |
| Young onset dementia (YOD)              | Dementia which develops in people under the age of 65years  |



# BIBLIOGRAPHY

Alzheimer's Society. (2022). Left to Cope Alone: the unmet support needs after a dementia diagnosis. left-to-cope-alone-after-diagnosis-report.pdf ([alzheimers.org.uk](https://www.alzheimers.org.uk))

Alzheimer's Society (2021) Regional variations: Increasing access to a dementia diagnosis report [https://www.alzheimers.org.uk/sites/default/files/2021-09/regional\\_variations\\_increasing\\_access\\_to\\_diagnosis.pdf](https://www.alzheimers.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf)

Alzheimer's Society (2021) Increasing diagnosis for people residing in a care home or hospital setting [https://www.alzheimers.org.uk/sites/default/files/2021-09/hospitals\\_and\\_care\\_homes\\_increasing\\_access\\_to\\_diagnosis.pdf](https://www.alzheimers.org.uk/sites/default/files/2021-09/hospitals_and_care_homes_increasing_access_to_diagnosis.pdf)

Alzheimer's Society (2021) Ethnic minority communities: Increasing access to a dementia diagnosis [https://www.alzheimers.org.uk/sites/default/files/2021-09/ethnic\\_minorities\\_increasing\\_access\\_to\\_diagnosis.pdf](https://www.alzheimers.org.uk/sites/default/files/2021-09/ethnic_minorities_increasing_access_to_diagnosis.pdf)

Alzheimer's Society (2020). The impact of COVID-19 on people affected by dementia. Available: [https://www.alzheimers.org.uk/sites/default/files/2020-08/The\\_Impact\\_of\\_COVID-19\\_on\\_People\\_Affected\\_By\\_Dementia.pdf](https://www.alzheimers.org.uk/sites/default/files/2020-08/The_Impact_of_COVID-19_on_People_Affected_By_Dementia.pdf)

Alzheimer's Society. (2020). Worst hit: dementia during coronavirus Worst-hit-Dementia-during-coronavirus-report.pdf ([alzheimers.org.uk](https://www.alzheimers.org.uk))

Alzheimer's Society (2015) Learning disabilities and dementia Factsheet number 430. [https://www.uhnm.nhs.uk/media/1112/factsheet\\_learning\\_disabilities\\_and\\_dementia.pdf](https://www.uhnm.nhs.uk/media/1112/factsheet_learning_disabilities_and_dementia.pdf)

Bartlett, R. (2022) Inclusive (social) citizenship and persons with dementia, Disability & Society Pages 1129-1145 <https://www.tandfonline.com/doi/full/10.1080/09687599.2021.1877115>

Carers UK (2020) Caring and COVID-19, Loneliness and use of services. <https://www.carersuk.org/news-and-campaigns/press-releases/covid-19-leaves-unpaid-carers-without-physical-and-mental-health-treatment>

DataRich (2022) [www.datarich.info](http://www.datarich.info)

Dementia Friendly Communities Richmond (2022) <https://www.ageuk.org.uk/richmonduponthames/our-services/dementia-friendly-communities-richmond/>

Department of Health & Social Care (2021) People at the Heart of Care: adult social care reform white paper <https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper>

HM Government (2012) Health and Social Care Act 2012 <https://www.legislation.gov.uk/ukpga/2012/7/contents>

HM Government (2014) Care Act 2014 <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

Hounslow & Richmond Community Healthcare NHS Trust (HRCH) – Strategic Plan 2018-2023 [https://www.hrch.nhs.uk/application/files/5315/7953/9562/HRCH\\_Trust\\_Strategic\\_Plan\\_2018-23.pdf](https://www.hrch.nhs.uk/application/files/5315/7953/9562/HRCH_Trust_Strategic_Plan_2018-23.pdf)

Livingston, G. (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission, The Lancet Commissions, Vol 396, Issue 10248, P413-446. [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext)

London Borough of Richmond upon Thames and NHS Richmond Clinical Commissioning Group (2016) Joint Dementia Strategy 2016-2021. [https://www.richmond.gov.uk/media/13380/joint\\_dementia\\_strategy\\_2016\\_21.pdf](https://www.richmond.gov.uk/media/13380/joint_dementia_strategy_2016_21.pdf)

London Borough of Richmond Upon Thames (2021) Joint Strategic Needs Assessment <https://www.richmond.gov.uk/jsna>

London Borough of Richmond upon Thames, Public Health (2020) Richmond Dementia Report: Emerging learning and recommendations in the context of COVID-19 across the local dementia prevention and care pathway. [https://www.richmond.gov.uk/media/21193/richmond\\_dementia\\_report.pdf](https://www.richmond.gov.uk/media/21193/richmond_dementia_report.pdf)

London Borough of Richmond upon Thames (2022) Communications campaign [https://www.richmond.gov.uk/news/june\\_2022/reduce\\_your\\_risk\\_of\\_dementi](https://www.richmond.gov.uk/news/june_2022/reduce_your_risk_of_dementi)

London Borough of Richmond (2020) The 2020-25 Carers Strategy [https://www.richmond.gov.uk/media/18967/richmond\\_carers\\_strategy\\_2020.pdf](https://www.richmond.gov.uk/media/18967/richmond_carers_strategy_2020.pdf)

Mukadam, N et al (2022) Incidence, age at diagnosis and survival with dementia across ethnic groups in

England: A longitudinal study using electronic health records, Alzheimer's & Dementia. <https://pubmed.ncbi.nlm.nih.gov/36047605/>

National Institute for Health and Care Excellence, (2021) Quality Standard [QS198] Suspected neurological conditions: recognition and referral <https://www.nice.org.uk/guidance/qs198>

National Institute of Health and Care Excellence (2021) Clinical Knowledge Summary. Dementia. <https://cks.nice.org.uk/dementia>

National Institute for Health and Care Excellence. (2019) NICE Guidance [NG127] Suspected neurological conditions: recognition and referral. <https://www.nice.org.uk/guidance/ng127>

National Institute of Health and Care Excellence. (2019) Quality Standard [QS184] Dementia <https://www.nice.org.uk/guidance/QS184>

National Institute for Health and Care Excellence. (2018). NICE guideline [NG97] Dementia: assessment, management and support for people living with dementia and their carers.. <https://www.nice.org.uk/guidance/ng97>

National Institute for Health and Care Excellence. (2015) NICE Guidance [NG16] : Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset. <https://www.nice.org.uk/guidance/ng16>

National Institute for Health and Care Excellence. (2011) Technology appraisal guidance [TA217] Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease. <https://www.nice.org.uk/guidance/ta217>

NHS England (2017), Dementia: Good Care Planning – information for primary care and commissioners. <https://www.england.nhs.uk/publication/dementia-good-care-planning-information-for-primary-care-and-commissioners/>

NHS Health Checks <https://www.nhs.uk/conditions/nhs-health-check/>

NHS Quality and Outcomes Frameworks <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/general-practice-data-hub/quality-outcomes-framework-qof>

Norton S, Matthews FE, Barnes DE, Yaffe K, Brayne C. Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. *Lancet Neurology*. 2014 Aug; 13(8): 788-94. Available from: [https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(14\)70136-X/fulltext](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(14)70136-X/fulltext)

Office for Health Improvement and Disparities (2022) Dementia: applying All Our Health [Internet].; Available from: <https://www.gov.uk/government/publications/dementia-applying-all-our-health/dementia-applying-all-our-health>

Office for National Statistics [www.ons.gov.uk](http://www.ons.gov.uk). (<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/202-slide>)

Olujoke A. Fakoya, Noleen K. McCorry & Donnelly, M. (2021) How do befriending interventions alleviate loneliness and social isolation among older people? A realist evaluation study. <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0256900>

Public Health Outcomes Framework (PHOF) 2022 <https://fingertips.phe.org.uk/profile/public-health-outcomes-framework>

Projecting Adult Needs and Service Information (PANSI) [www.pansi.org.uk](http://www.pansi.org.uk).

Projecting Older People Population Information (POPPI) [www.poppi.org.uk](http://www.poppi.org.uk)

Richmond Carers Strategy 2020-25 [https://www.richmond.gov.uk/media/18967/richmond\\_carers\\_strategy\\_2020.pdf](https://www.richmond.gov.uk/media/18967/richmond_carers_strategy_2020.pdf)

Richmond Dementia Service Directory [https://www.richmond.gov.uk/media/20317/richmond\\_dementia\\_support\\_directory.pdf](https://www.richmond.gov.uk/media/20317/richmond_dementia_support_directory.pdf)

Royal College of Psychiatrists (2019) Memory Clinic Audit . [www.england.nhs.uk/london/wpcontent/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf](http://www.england.nhs.uk/london/wpcontent/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf)

South West London Integrated Care Partnership – Richmond (2022) <https://www.southwestlondonics.org.uk/richmond/>

Victor, C R et al. (2020) Prevalence and determinants of loneliness in people living with dementia: Findings from the IDEAL programme. [Online] *International Journal of Geriatric Psychiatry*. <https://doi.org/10.1002/gps.530>

## Produced by the Richmond Dementia Prevention Leadership Group

**Chair Dr Nike Arowobusoye,**  
Consultant in Public Health

**Tammy Macey,**  
Public Health Senior Lead

**Dr Lisa Wilson,**  
Public Health Lead

October 2022

## ACKNOWLEDGMENTS

**Adult Social Care** Paul Banks, Nadine Hassler, Steve Shaffelburg and Ged Taylor.

**Co-production Group:** Bruno Meekings RCVS (Chair) and Fiona Wright

**Care and Support Partnership:**

**Dementia Friendly Richmond:** Sara Wilcox., Rob Burton, Gavin Shand

**Dementia Prevention and Care Leadership Group (DPLG):**

Dr Nike Arowobusoye: Public Health Consultant, LBRuT DAsCPH (Chair); Rob Burton: Chief Executive Officer, Age UK Richmond; Nina Jalota /Theresa Keegal: Community Dementia Practitioners, Hounslow and Richmond Community Healthcare NHS Trust; Dr Stavroula Lees: Clinical Lead for Mental Health, NHS Southwest London CCG; Tamatha Macey: Senior Public Health Lead, LBRuT DAsCPH; Cathy McCann: Dementia Lead, West Middlesex Hospital; Edna Porter, Head of Community Services, LBRuT DAsCPH; Lydia Russell: Service Lead Dementia and Delirium, Kingston Hospital NHS Foundation Trust; Steve Shaffelburg: Commissioning Manager, LBRuT DAsCPH; Arlene Thomas-Dickson: Senior Transformation Manager Mental Health & Personalisation (Richmond), NHS Southwest London CCG; Dr Lola Velazquez: Consultant Psychiatrist, Barnes Memory Assessment Service Southwest London and St George's Mental Health Trust; Tanya Williams: Dementia Connect Local Services Manager Richmond and Kingston, Alzheimer's Society, Alzheimer's UK Richmond.

**Public Health Team:** Dr Nike Arowobusoye, Sarah Fleming, Tamatha Macey and Dr Lisa Wilson.

**Richmond Community Health Champions:** Maria Cantisani, Lyn Cox, Margaret Dangoor, Bisakha Ghose, Leah Murray, Shara Ross and Lesley Walsh. Patricia Kanneh- Fitzgerald (coordinator),

**RUILS:** Jeanne Davey, Manager

**Lead member for Adult Social Care & Health and Public Health, LBRuT:**  
Councillor Piers Allen

**Dementia Member Champion, LBRuT:** Councillor Clare Vollum