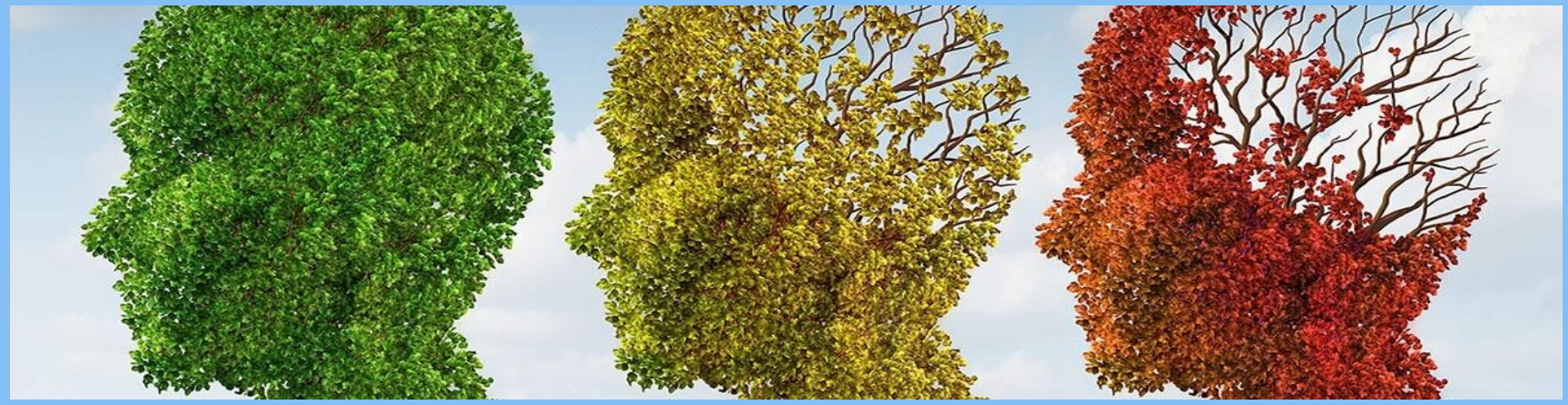
Dementia Needs Assessment



Key Findings and lessons learned

Dementia prevention T&F Group (14/6/24)

Dr Leidon Shapo, Public Health Lead (Adults)

Agenda (14 June 2024)

1. **Introductions 11:00 |** (All; 5-10 minutes)

2. **Dementia prevention needs assessment: key findings and lessons learned | 11:45** (LShapo; 30mins)

3. **The dementia pillar as part of the Older people strategy 2023-26** | **11:55** (briefing from V.Pugh; 10mins)

4. **Aims & Objectives of the dementia T&FG including the frequency of meetings** | **12:10** (LS/All; 10-15 mins)

5. **Planning to develop a dementia awareness pack for residents | 12:20** (LS/WA; 5 min)

6. **Any Other Business & Next Meeting | 12:25** (5min)

Health Needs Assessments form part of Slough Joint Strategic Needs Assessment (JSNA) process

BACKGROUND

The Joint Strategic Needs Assessment (JSNA) is the ongoing process through which we seek to identify the current and future health and wellbeing needs of our local population.

- The JSNA document is what we use in Slough to assess the current and future healthcare and wellbeing needs of our residents.
- Local authorities and ICBs have equal and joint duties to prepare JSNAs and joint local health and wellbeing strategies through their Health and Wellbeing Boards.
- The Slough Joint Wellbeing Board has a duty to improve the health and wellbeing for those who live in Slough. The Slough Joint Wellbeing Strategy, developed by the Slough Wellbeing Board is based on the needs identified by the JSNA.

This document forms part of those resources Berkshire East JSNA (berkshirepublichealth.co.uk)

This needs assessment aimed to better understand the local picture and changes over time

Aims & Objectives

Aims: The main aims of the needs assessment were to

- **improve the current understanding of the local burden of dementia** by looking at changes over time, and
- **support the dementia care integration process and quality of care for our local population.**

Key Objectives

- Describe the national policy and strategic context
- Identify modifiable risk factors to dementia and their lifespan cumulative impact
- ***Describe the local picture of dementia in Slough***
- ***Describe evidence-based interventions for prevention and timely diagnosis***
- Describe the local provision of dementia services and better understand our dementia care model
- Inform 2nd phase of this project to **support the Older People Strategy and our local dementia care action plan.**

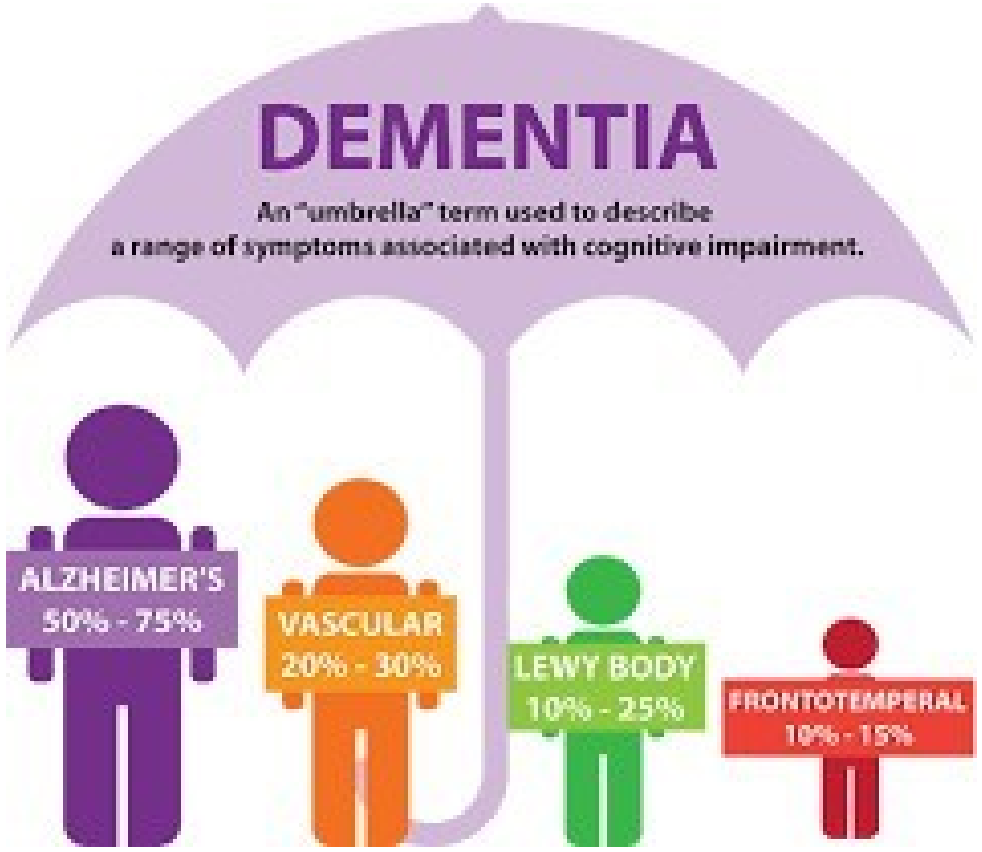
Contents

Dementia: A significant loss of cognitive abilities that interferes with daily life including social or occupational functioning

Dementia is progressive and largely irreversible

- 50-70% is due to Alzheimer's disease, which is a poorly understood neurodegenerative disease with genetic, medical and behavioural risk factors; and
- Vascular dementia (20-30%), dementia with Lewy bodies - can co-exist with Alzheimer's and many share risk factors.

Dementia can lead to a reduced quality of life, ill-health and premature mortality and is one of the leading causes of death in the UK



Dementia vs. Alzheimer's Disease: What Is the Difference? | alz.org

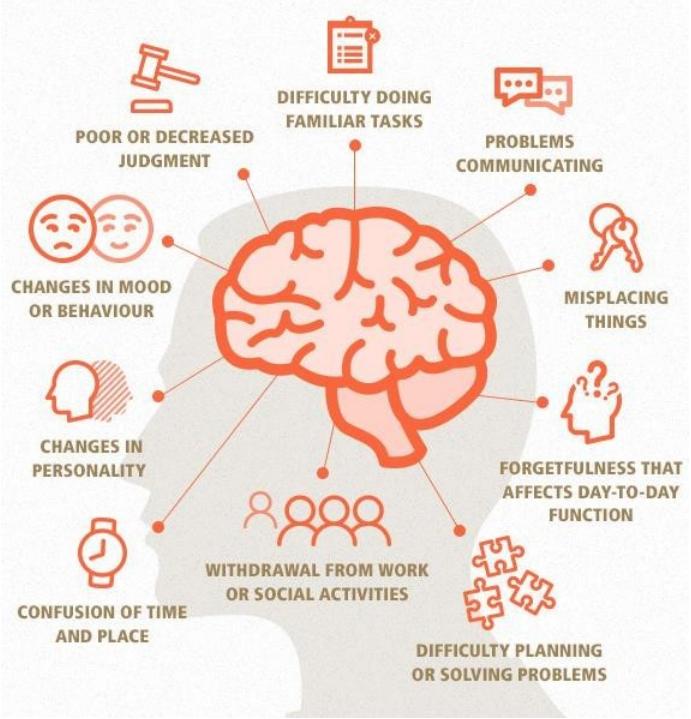
Types of Dementia | Dementia Friendly Wyoming (dfwsheridan.org)

The clinical definition and main symptoms

‘Dementia’ is medically defined as a clinical syndrome (group of symptoms) characterised by difficulties with one or more areas of mental function. These areas may include memory, language, ability to complete activities of daily living, behavioural changes including self-neglect and out of character behaviour and psychiatric problems.

Symptoms of dementia include:

- **Loss of memory** - for example, forgetting the way home from the shops, or being unable to remember names and places, or what happened earlier the same day
- **Mood changes** - particularly as parts of the brain that control emotion are affected by disease
- People with dementia may also feel sad, frightened or angry about what is happening to them
- **Communication problems** - a decline in the ability to talk, read and write. In the later stages of dementia, the person affected will have problems carrying out everyday tasks and will become increasingly dependent on other people.



Non-modifiable risk factors for dementia

Age is the most significant non-modifiable risk factor for the development of dementia.

- **Above the age of 65**, a person's risk of developing Alzheimer's disease or vascular dementia doubles approximately every 5 years. It is estimated that dementia affects one in 14 people over 65 years old, and one in six over 80 years old.

- Alzheimer's disease is known to be more common in **women**, even when adjusted for greater life expectancy of women. Women are disproportionately affected by dementia, both directly and indirectly. Women experience higher disability-adjusted life years and mortality due to dementia, but also provide 70% of care hours for people living with dementia.

- International research has demonstrated differences in rates of diagnosis between certain **ethnic groups.** Evidence indicates people from South Asia and people of African or Afro-Caribbean origin seem to develop dementia more often.

- Whilst more than 20 genes have been identified to not directly cause dementia, there is a clear pattern of inheritance of dementia in affected families.

1. Dementia UK: The Full Report, Alzheimer's Society Prevalence by age in the UK - Dementia Statistics Hub
2. Dementia (who.int)

Ethnicity is another important non-modifiable risk factor for dementia

- **More than 25,000 older black and minority ethnic people live with dementia in the UK**, in part due to vascular risk factors such as hypertension often found in African-Caribbean and South Asian UK populations. [1]
- **Inequalities** between and within communities are having a significant impact on black and minority ethnic people living with dementia and their families.
- There continue to be **challenges at all stages** of the dementia pathway, from prevention through diagnosis, care and end of life. Knowledge of dementia is still quite poor across communities, and even among professionals. This has a significant impact on issues such as prevention.
- **Black and minority ethnic carers** are still poorly supported in most of England and continue to face barriers to participation.
- **Engagement with social and health care services** may be resisted by some black and minority ethnic communities because they fear discrimination, or they find services are difficult to access. [2]
- **Access and awareness** for those at higher risk: There's evidence that people from minor ethnic communities are not sure where or how to find information about dementia. This is exacerbated by language barriers or when people have lost cognitive skills, or if online information is not available in community languages.

1. Dementia and Black, Asian and minority ethnic communities - Race Equality Foundation
2. Black and minority ethnic (BME) communities and dementia - SCIE

Social isolation and loneliness are linked to added risk for developing dementia

There is strong evidence that many adults aged 50 and older are socially isolated or lonely – putting their health at risk. [1]

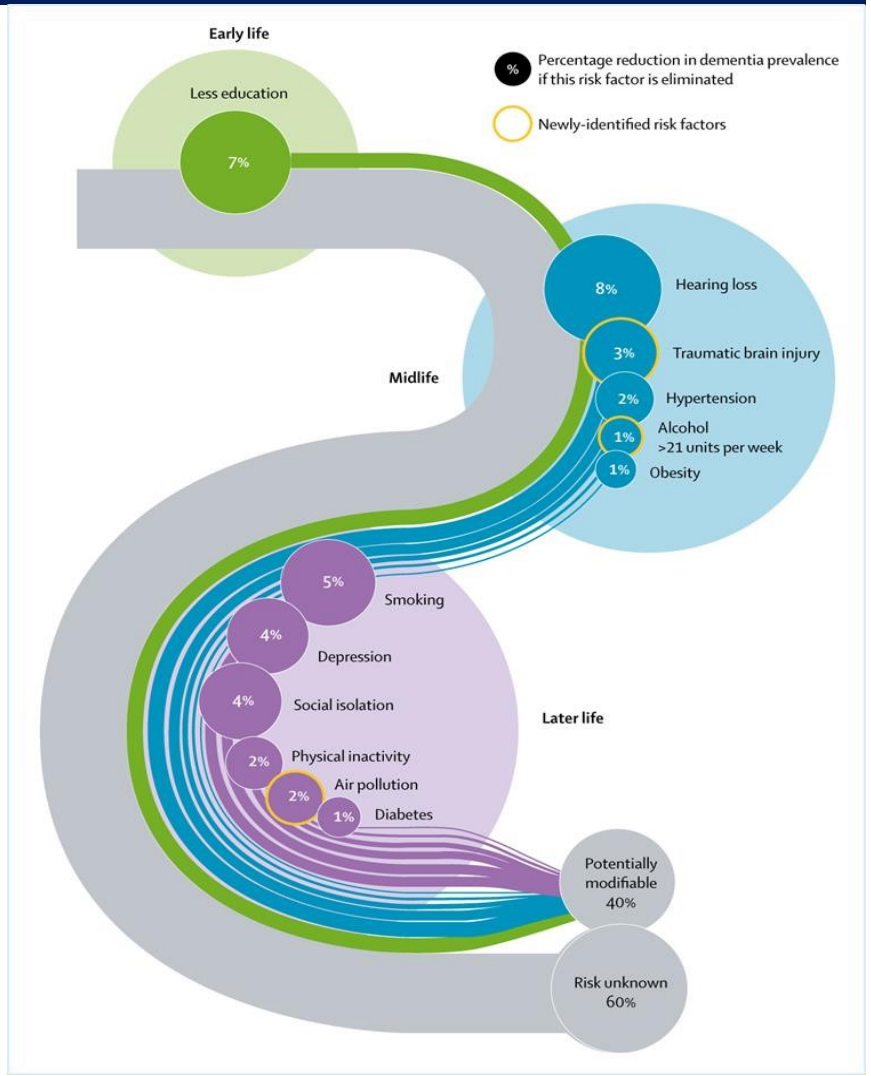
- Social isolation significantly increased a person's risk of premature death - rivalling smoking, obesity, and physical inactivity. Social isolation was associated with about a 50% increased risk of dementia. [2]
- **One-third of people with mild-to-moderate dementia experience loneliness**. 30% are moderately lonely and 5% are severely lonely, reports one of the first major studies to look at the issue. These figures are comparable to the general population of older people.
- People with dementia who live alone, and who experience social isolation, depression and lower quality of life are more likely to feel lonely. Some researchers found no association between loneliness and dementia-specific factors.[3]
- Loneliness was associated with higher rates of depression, anxiety, and suicide.

1. Summary report: The State of Ageing 2022 | Centre for Ageing Better (ageing-better.org.uk)
2. Loneliness and Social Isolation Linked to Serious Health Conditions (cdc.gov)
3. Social isolation linked to lower brain volume and higher dementia risk - Alzheimer's Research UK

Prevention: we need to focus on the life-course risk factors

"We need to study risk factors and cognitive impacts long before a diagnosis"

- Growing evidence for **12 modifiable risk factors for dementia**
- **Early-life risks, affect cognitive reserve; midlife and later-life risk factors (not simply age related) influence reserve and triggering of brain changes**.
- Also, there is sufficiently strong evidence, from a population-based perspective, to suggest that regular physical activity and management of cardiovascular risk factors reduce the risk of cognitive decline and may reduce the risk of dementia.
- Culture, poverty, and inequality are key drivers of the need for change. Individuals who are most deprived have greatest needs and will derive the highest benefit.

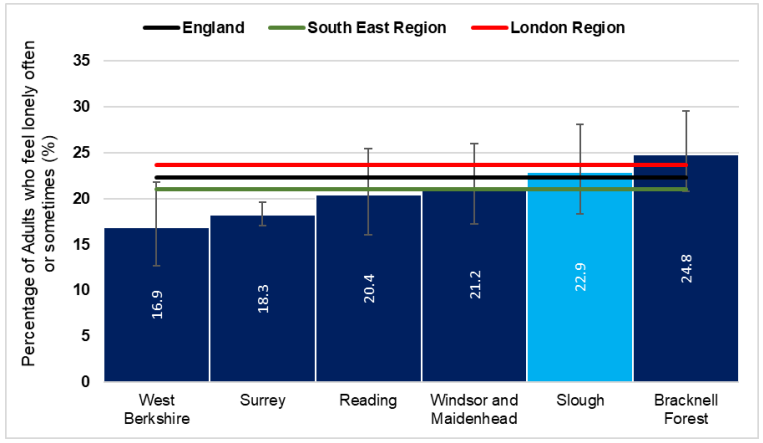


Social isolation/loneliness, deprivation & lifestyle risks are all responsible for developing dementia and the disease severity

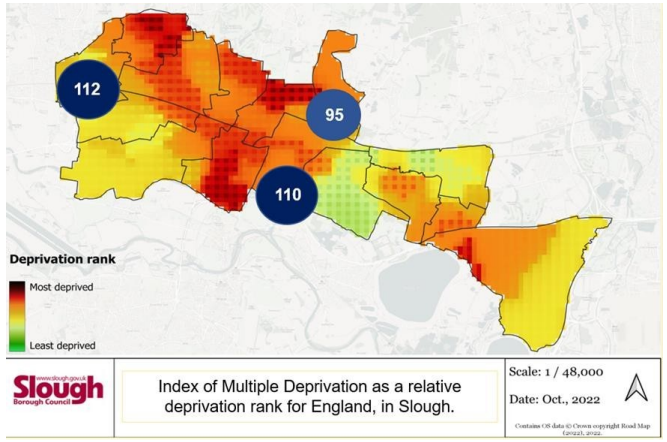
Around a fifth of Slough adults feel lonely (often/sometimes) and that slightly higher than SE. **A third of Slough of social care users** (among those 65 and over) **report insufficient social contacts** and feeling significantly isolated – a figure that is lower than SE and England average.

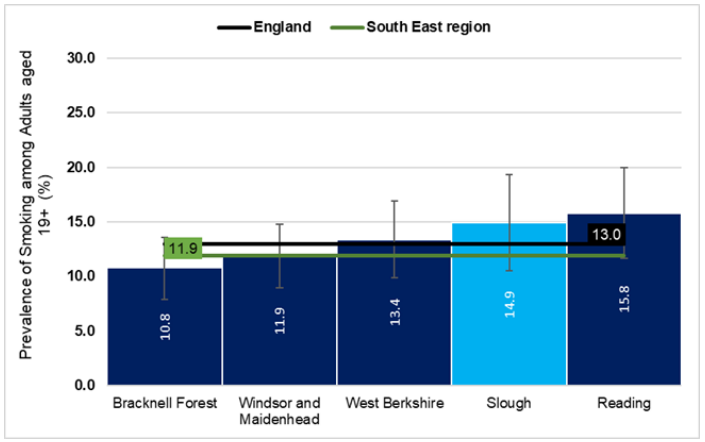
***Levels of deprivation and dementia risk*.** A large proportion of dementia deaths in England and Wales may be due to socioeconomic deprivation (according to new research led by Queen Mary University of London).

Lifestyle risk factors: Smoking and excess drinking are important modifiable risk factors for dementia. Overall, the evidence derived from systematic reviews have estimated that smoking confers between a 30-50% increased risk of developing dementia.



Source: OHID/PHE Fingertips





Source: OHID/PHE Fingertips

Contents

NICE guidance on dementia – policy context

The latest NICE guideline covers diagnosing and managing dementia (including Alzheimer's disease). It aims to **improve care by making recommendations on training staff and helping carers to support people living with dementia**. [1]

NICE has also produced a guidance on mid-life approaches to delay or prevent the onset of dementia (NG16).

- The aim was to delay the onset of disease progression to increase the amount of time that people can be independent, healthy and active in later life. [2]

Changing specific risk factors and behaviours can reduce the risk of dementia, disability and frailty for many people. These changeable lifestyle factors, are the focus of this guideline.

Statement 1 People accessing behaviour change interventions and programmes in mid-life are advised that the risk of developing dementia can be reduced by making lifestyle changes.

Statement 2 People with suspected dementia are referred to a specialist dementia diagnostic service if reversible causes of cognitive decline have been investigated.

Statement 3 People with dementia are given the opportunity to discuss advance care planning at diagnosis and at each health and social care review.

Statement 4 People with dementia have a single named practitioner to coordinate their care.

Statement 5 People with dementia are supported to choose from a range of activities to promote wellbeing that are tailored to their preferences.

Statement 6 People with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress.

Statement 7 Carers of people with dementia are offered education and skills training.

Source: Quality statements | Dementia | Quality standards | NICE (QS184; 2019)

1. Overview | Dementia: assessment, management and support for people living with dementia and their carers | Guidance | NICE, NICE NG97, 2018
2. Guideline on mid-life approaches to delay or prevent the onset of dementia (NG16), 2015

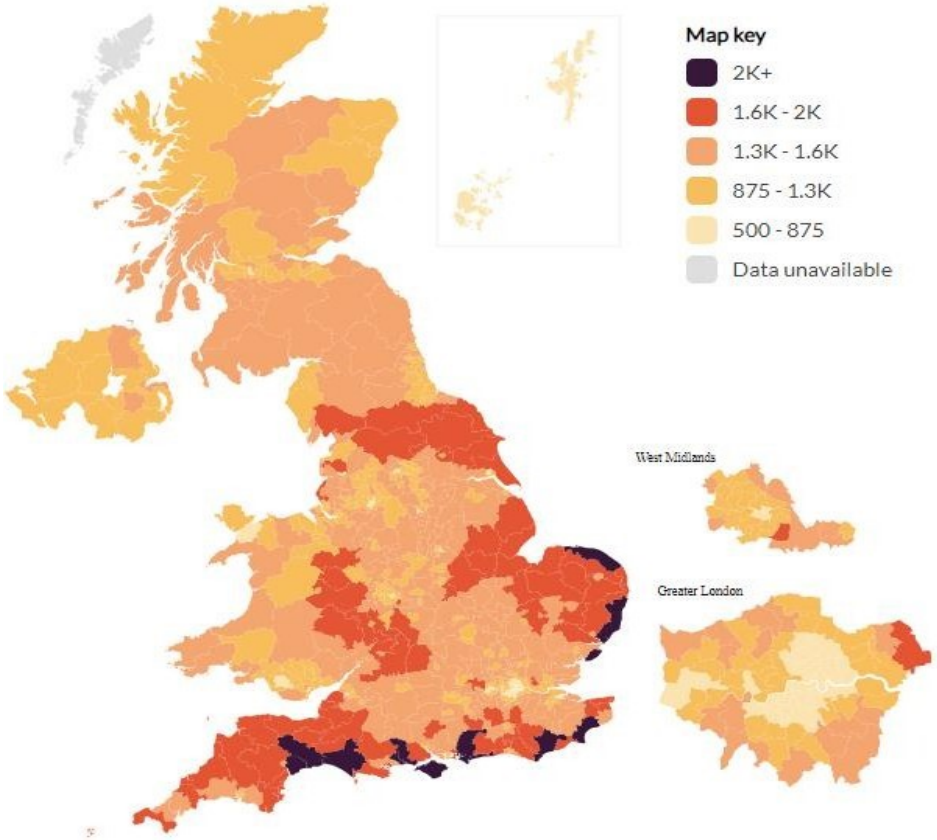
Contents

National dementia - Key statistics

Dementia affects around 944,000 people across the UK (2021) and the numbers are set to rise to over a **1.1 million by 2030** and are expected to increase to 2 million by 2051.

Dementia has a greater impact on women as the prevalence among women is higher than men and most carers are women**.**

- There are 209,600 new cases of dementia in the UK each year.
- **1 in 2 of us will be affected by dementia in our lifetime**; either by caring, developing the condition, or both.
- There are over 25,000 people with dementia from **ethnic minorities** in England and Wales, and this is estimated to rise to nearly 50,000 by 2026.
- Of all people with dementia in the UK, 57.7% have severe dementia.
- Of the four countries, **England has the highest overall prevalence rate of dementia among older people** (7.1%).

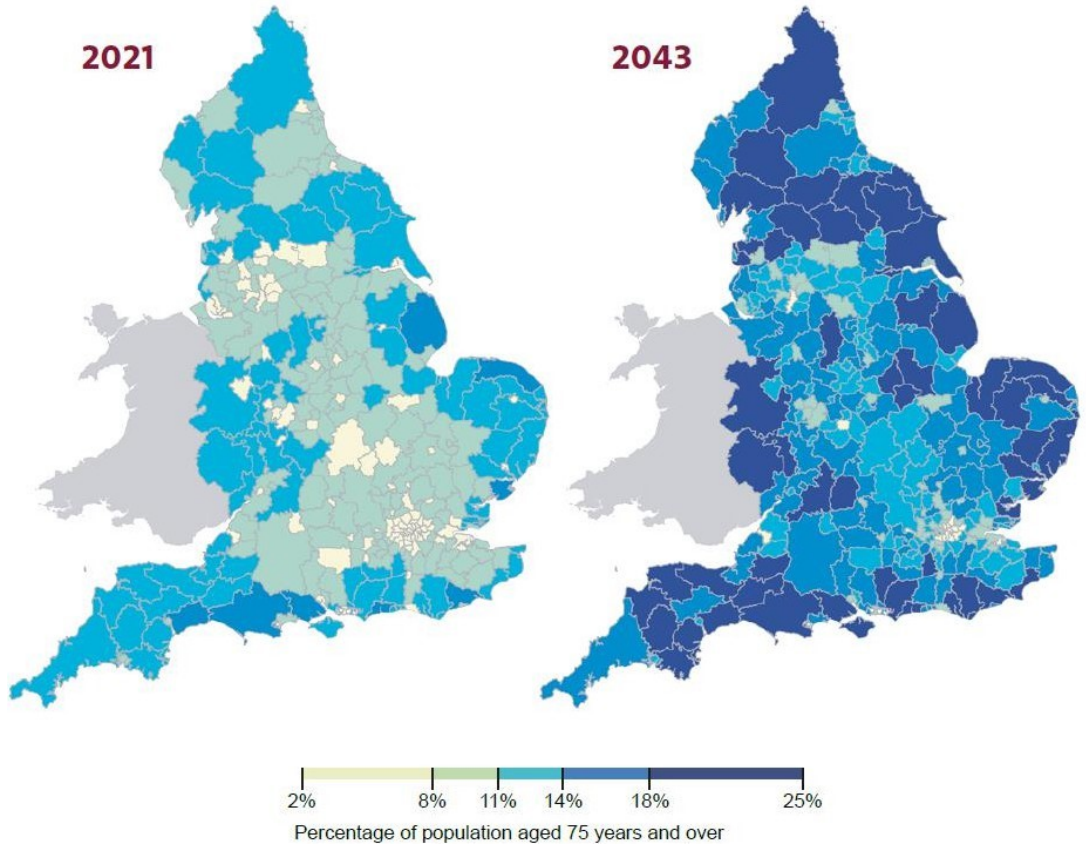


Statistics about dementia - Dementia Statistics Hub

We are all getting older… even Slough

Age is the most significant non-modifiable risk factor for the development of dementia

- Overall, the population of Slough increased by 13.0%, between 2011 and 2021 with an increase of 9.3% in the population aged 65 and over.
- **The increase in complexity of need is more important for Slough** than the slow increase in older age population that is expected to be more significant after 2035.



Chief medical officers annual report 2023 health in an ageing society

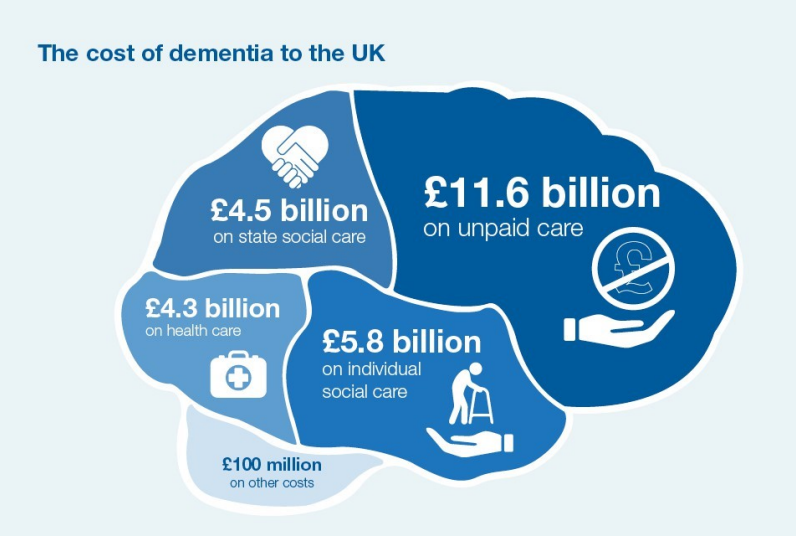
Source data: Office for National Statistics (ONS), 2021 mid-year estimates by local authority,[3] and 2018-based subnational population projections for 2043[4]

The cost of dementia care remain a significant burden for individuals affected and our healthcare services

The total cost of care for people with dementia in the UK is £34.7billion (an average annual cost of £32,250 per person with dementia), **and two-thirds of this cost is currently being paid by people with dementia and their families, either in unpaid care or in paying for private social care**

The cost is set to rise sharply over the next two decades, to £94.1billion in 2040.

- Dementia costs are made up of healthcare costs (costs to the NHS), social care costs (costs of homecare and residential care), and costs of unpaid care (provided by family members).
- The largest proportion of this cost, 45%, is social care, which totals £15.7billion.
- Social care costs are set to nearly triple over the next two decades, to £45.4billion by 2040**.**
- At the community level, the cost of caring for individuals with dementia **is similar to cancer, and greater than heart disease and stroke**.



Source: Health matters: midlife approaches to reduce dementia risk - GOV.UK

What are the costs of dementia care in the UK? | Alzheimer's Society

Hospital stay and discharge for people with dementia

At least 25% of general hospital beds are occupied by people living with dementia. People with dementia often experience longer hospital stays, delays in leaving hospital and reduced independent living.

On average people with dementia stay more than twice as long in hospital then other patients aged over 65. Evidence shows that:

- Whilst longer hospital stays for older people have been linked to worse health outcomes and an increase in care needs upon discharge, changes in the surrounding environment can lead to increased anxiety and stress for a person with dementia, and therefore short stays should be avoided if possible. [1]

A qualitative review revealed relatively small changes could be made to reduce delayed discharge for people living with dementia following an acute hospital stay. [2]

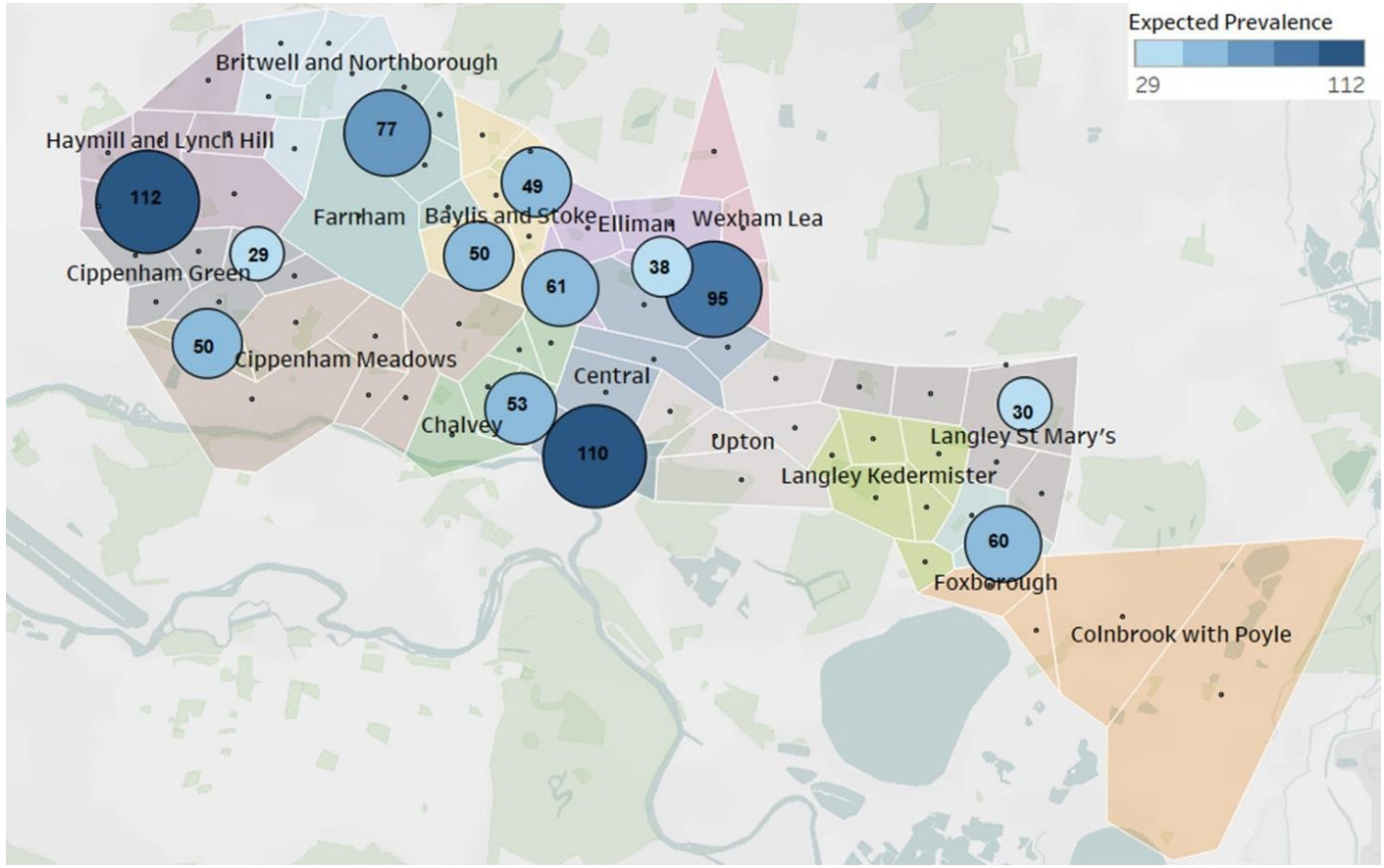
- Minor improvements across rehabilitation practices, obtaining a clinical history, documentation, joint working and supporting family involvement have the potential to result in a timely discharge.

The transition between hospitals and care homes is a well-documented area of poor care leading to adverse outcomes including costly re-hospitalisation

1. Hospital care | NICE impact dementia | Reviewing the impact of our guidance | Measuring the use of NICE guidance | Into practice | What we do | About | NICE
2. Reducing delayed transfer of care in older people National Institutes of Health (.gov) https://www.ncbi.nlm.nih.gov › articles › PMC9700150 (google.co.uk)

How much Dementia cases are we seeing in Slough?

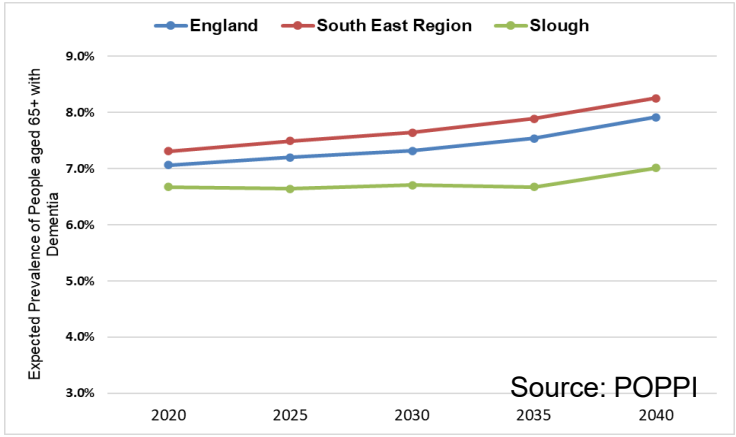
- The dementia QoF figures shown on the map represent both the recorded (diagnosed cases) and estimated (undiagnosed cases) for each GP practice area in Slough.
- The evidence suggest that dementia prevalence tend to be higher in areas with the highest proportion of individuals over 65 and areas with a high concentration of care homes.
- This is not yet the case for Slough, but **we should monitor and reflect on any demographic changes and landscape risk factors associated with the cognitive decline and dementia prevalence in the future**

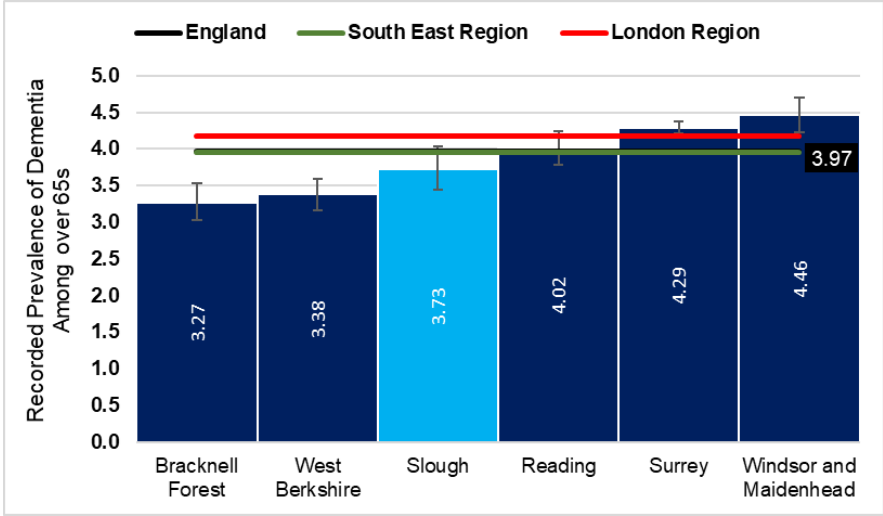


Source: Dementia estimates were calculated using GP Practice level QoF 2021/22 Prevalence and adding the estimated 40% of undiagnosed cases locally

Dementia prevalence locally and trends over time

- **The estimated dementia** prevalence for Slough has remained at 0.4% of the total population since 2014/2015. This could be due to Slough having relatively young population compared with England and the Southeast, but also due to lack of awareness, access to healthcare and other cultural differences.
- The estimated prevalence of dementia among those aged 65+ in Slough is expected to remain approximately just over 6.5% with a slight increase from 2035 onwards. The expected prevalence is projected to remain lower than both national and regional rates over time.
- **The recorded prevalence of dementia** among over 65s in Slough has remained just under 4% over the last few years and is lower than both the regional and national averages (although statistically similar in 2020).





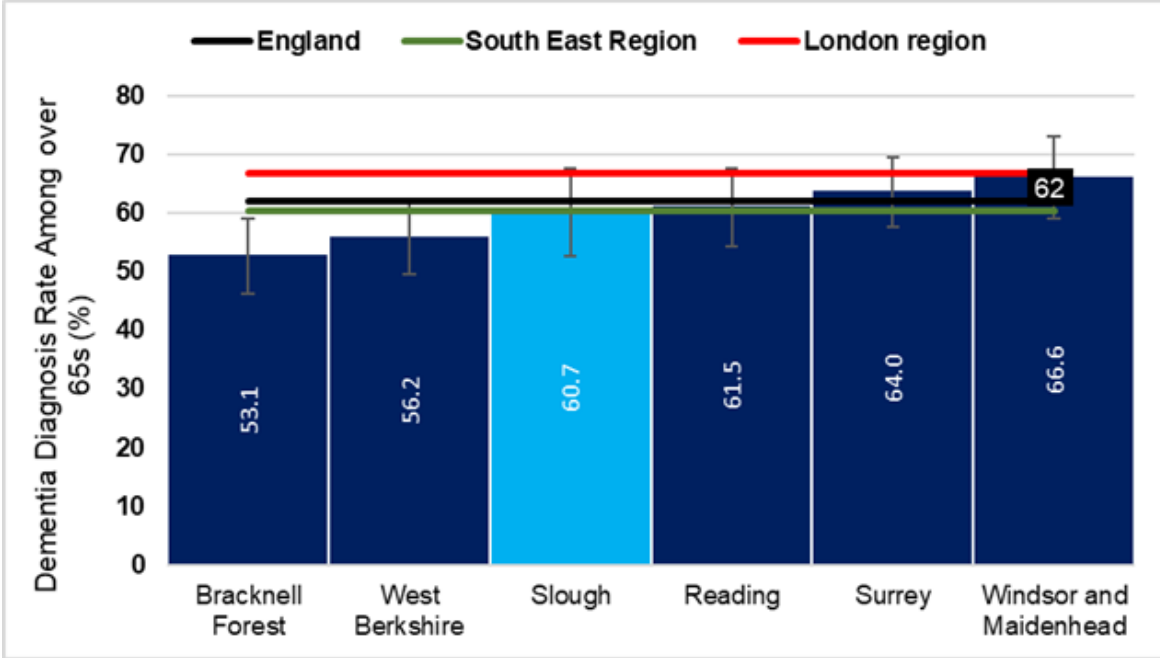
Source: OHID (Local Health Indicators)

The importance of knowing those that live with undiagnosed dementia in Slough

As of 2022, the estimated dementia diagnosis rate for Slough was 60.7% which is comparable to SE region and England.

Research shows that a timely diagnosis of dementia can have a significantly positive impact on a person's quality of life.

- Figures from the NHS show that 983 people aged 65 and older in Slough were estimated to have dementia in March 2023. Of them, 587 (59.7%) had a formal diagnosis. **It meant that 393 (40.3%) of people believed to have dementia in the area did not have a diagnosis**. [1]
- There is evidence that shows a dementia diagnosis gap in London (number of those with a diagnosis vs. the estimated prevalence number) which is attributable to issues in coding [2].

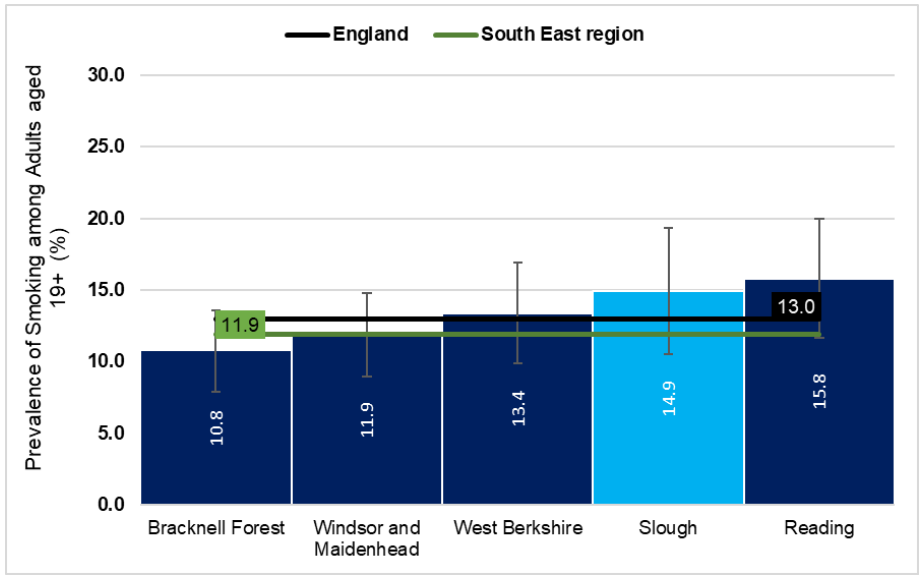


Source: OHID/PHE Fingertips (2022)

1. Primary Care Dementia Data, January 2023 - NHS Digital)
2. DDR-coding-GP-guide-October-2022.pdf (england.nhs.uk)

Smoking and excess drinking as dementia risk factors

- **Smoking and excess drinking were two of the 12 modifiable risk factors highlighted in the latest Lancet Commission on dementia risk.** Overall, the evidence derived from systematic reviews have estimated that smoking confers between a 30-50% increased risk of developing dementia.
- The estimated prevalence of smoking in Slough in 2021/22 was 14.9% and that is higher than both national (13%) and regional (11.9%) rates, there was no evidence to suggest the rates were statistically higher.
- The directly standardised rates for alcohol related mortality in Slough was also higher than national and regional rates at 40.4%, but there was no evidence to suggest a statistical significance for the difference.



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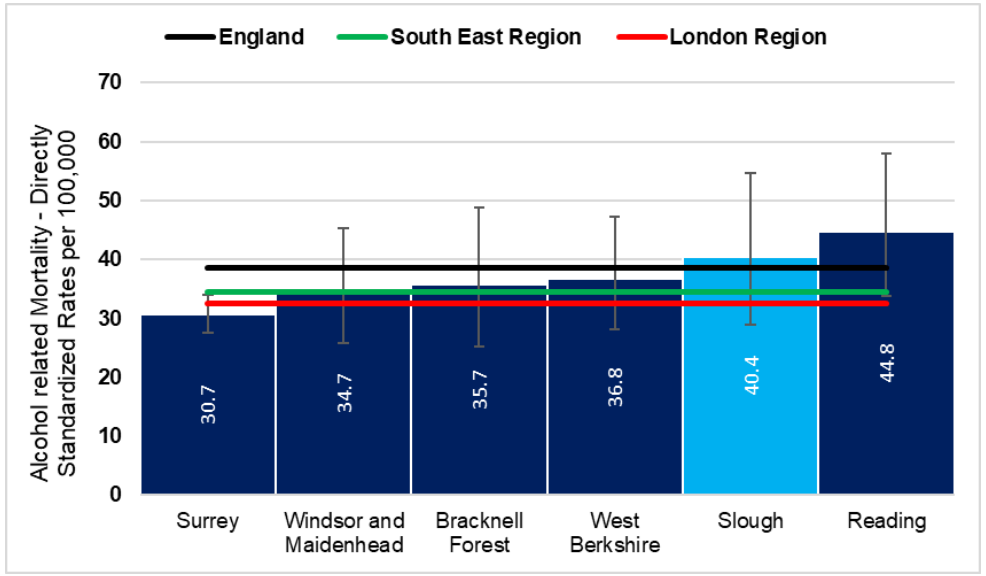
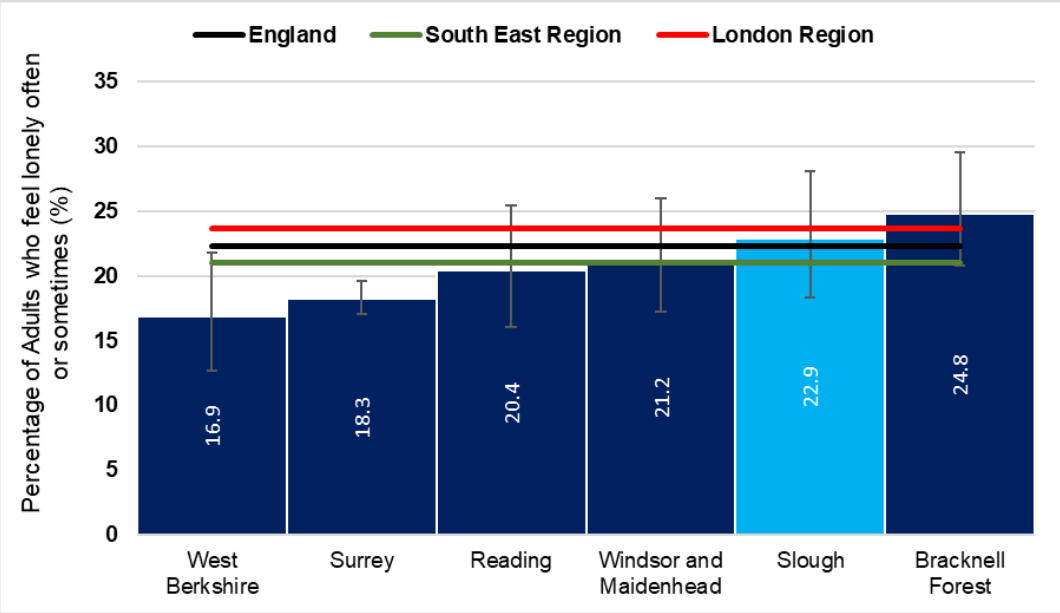
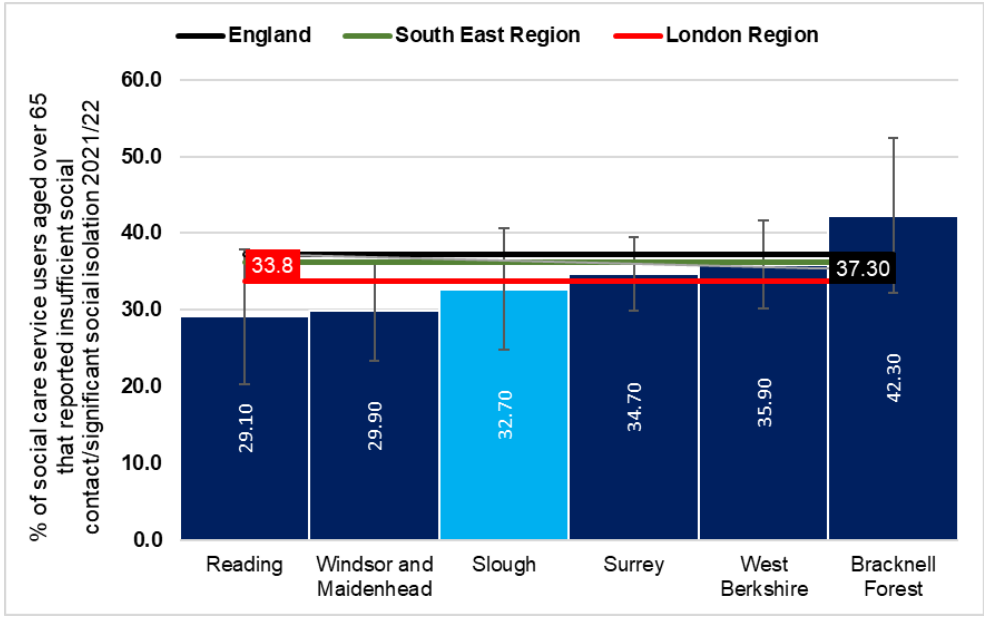


Source: OHID/PHE Fingertips

Both social isolation and loneliness are risk factors for developing dementia and the disease severity

- **Around a fifth of Slough adults feel lonely** (often/sometimes) and that slightly higher than SE but lower than London and comparable to England.
- **A third of Slough of social care users** (among those 65 and over) **report insufficient social contacts** and feeling significantly isolated – a figure that is lower than SE and England average.

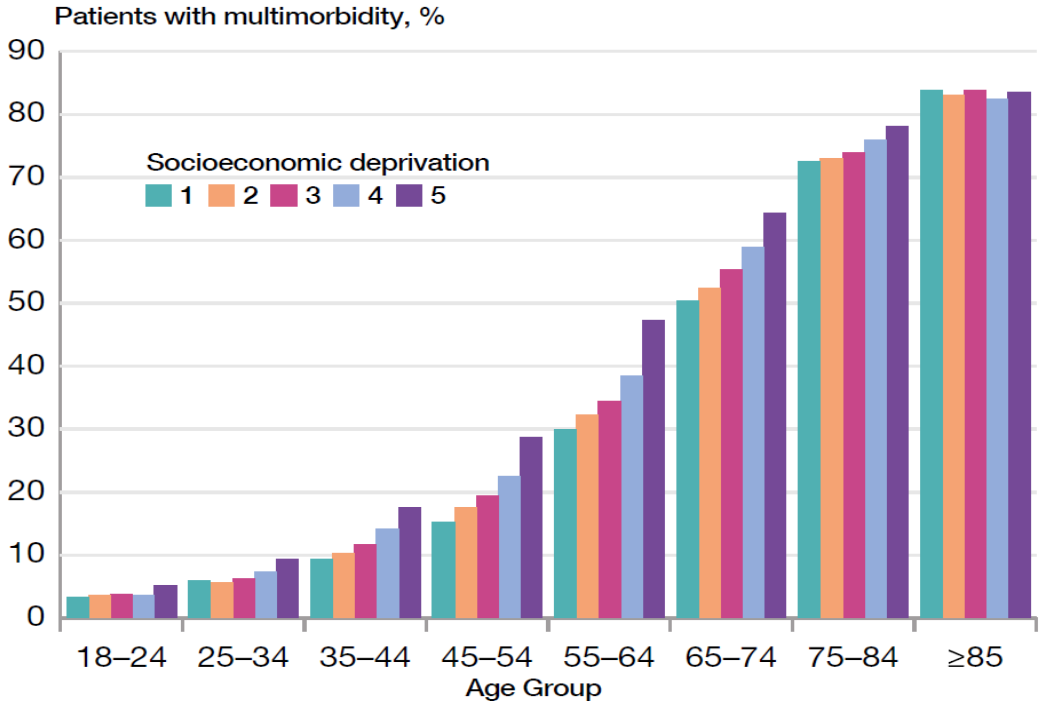




Source: OHID/PHE Fingertips

As we age, we accumulate conditions. Individuals with dementia are at a greater risk for certain health conditions

Figure 4: Prevalence of multimorbidity (2 or more conditions) by age and deprivation



(Index of Multiple Deprivation quintiles: 1 = least deprived, 5 = most deprived)
Source data: Cassell A and others (2018). The epidemiology of multimorbidity in primary care: a retrospective cohort study. British Journal of General Practice7
Image source: Chief Medical Officer's Annual Report 2020, Health trends and variation in England

chief medical officers annual report 2023 health in an ageing society

Dementia: comorbidities in patients - data briefing - GOV.UK

Two in three seniors over the age of 65 have two or more chronic diseases. This is known as comorbidity.

A PHE briefing (2019) shows findings from the analysis of a sample of anonymised PC records in relation to the prevalence of diagnosed comorbid conditions of patients with a diagnosis of dementia.

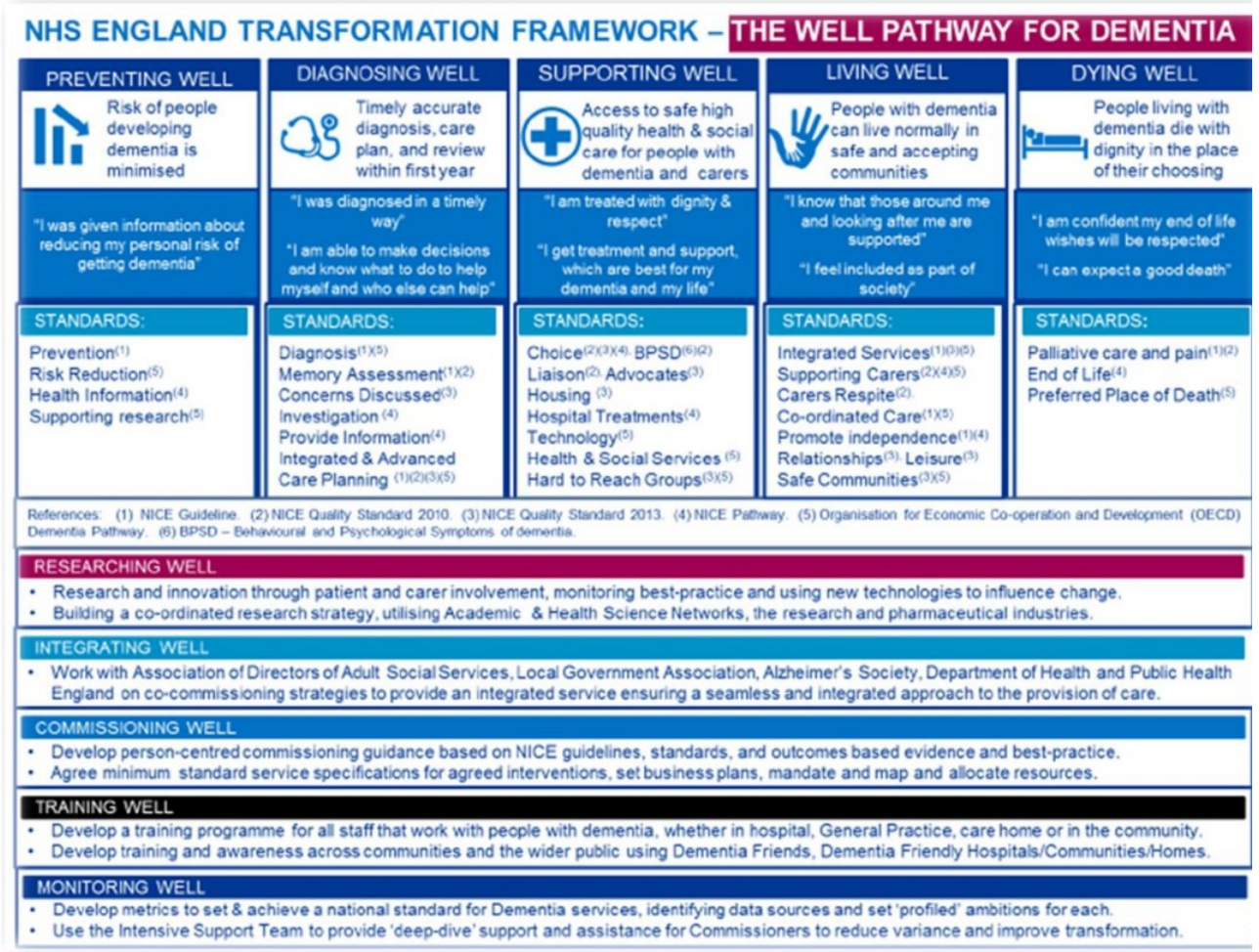
- For patients with dementia, 44% have a diagnosis of hypertension, between 17% and 20% have a diagnosis of diabetes, stroke or TIA, CHD or depression, while between 9% and 11% have a diagnosis of Parkinsonism, chronic obstructive pulmonary disease or asthma.
- Patients with dementia are more likely to have multiple health conditions. A total of 22% with 3 or more comorbidities and 8% with 4 or more comorbidities, compared to 11% and 3% respectively in the all-patient group.

Contents

The NHS Well Pathway for Dementia

National and Local strategy and supporting guidance that influenced the direction of our Dementia Work includes:

- The Prime Minister's Challenge on Dementia (2016)
- Care Act (2014)
- NHS Long Term Plan (2019)
- NICE: Dementia Assessment, management and Support (2018)
- Better Care Closer to Home (2017)
- East Berkshire Plan (2020)
- Slough Borough Council Plan (2020-2025)



NHS England Dementia wellbeing pathway

Developing a dementia care action plan for Slough – Our care model

The Slough Health and Care Plan is a key part of our Vision for Slough. It focusses on the Integration of Health & Social Care including 'Ageing well' as one of the ICS's pillars. [1]

Dementia Care Model locally

2018-2019: Public health developed the Dementia Need assessment titled: 'Living in Slough with Dementia'. Since then, the following progress has been made:

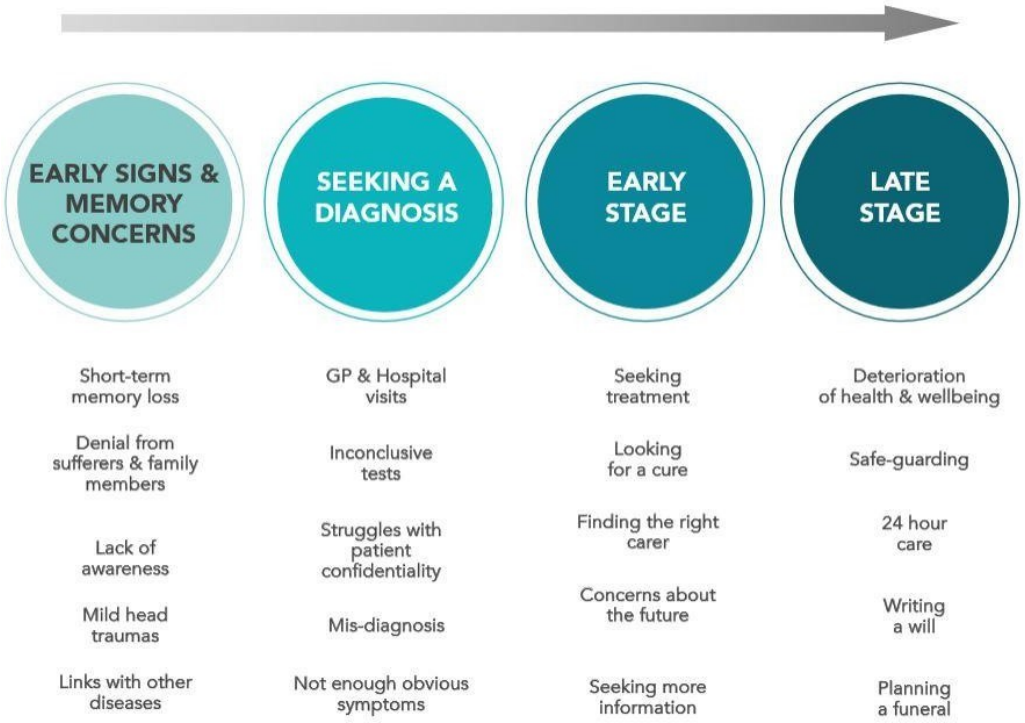
- Promoted **positive behaviour change**: Slough has incorporated many programs including NHS Health Check using the MECC model, to raise awareness of dementia as part of the Integrated Health and Wellbeing services commissioned by S4H.
- **The Memory Clinic** – which now have a group utilising Cognitive Stimulation Therapy that is leading to more positive outcomes including improvement to individual wellbeing for patients with dementia.
- **Adult Social Care support** - ASC team coordinate their approach jointly with PH to improve the awareness and to encourage people to make use of the council's leisure and library services to tackle physical inactivity, social isolation and improve local connections for those feeling lonely.
- In terms of **dementia care plans** – 51.5% of dementia care plans were reviewed in Slough over the last 12 months, and that's the second highest in the SE region, and higher than the national and London region.

1. PowerPoint Presentation (slough.gov.uk)
2. Dementia Care Strategy: A Progress Update Meeting of Health Scrutiny Panel, Thursday, 21st November, 2013 6.30 pm (Item 35.)

Integrated services provision both at national and local level

Dementia pathway – what each work stream offers

- **Preventing Well** – (Prevention, Risk Reductions, Health Information, Supporting research)
- **Diagnosing Well** - (Diagnosis, Memory Assessment, Concerned Discussed, Investigation, Provide Information Integrated and advanced, Care Planning)
- **Living Well** – (Integrating services, Supporting Carers, Carers respites, Coordinating Care, Promoting Independence, Relationships, Leisure, Safe Communities)
- **Supporting Well** – (Choice, Advocates, Liaison, Housing, Hospital treatment, Technology, Health and Social Care Services, Hard to Reach Groups)
- **Dying Well** – EoLC (Palliative care and pain, End of Life, Preferred Place of Death)



Mapping the Dementia Diagnosis Journey to Improve Self-Guided Support | Alzheimer's Society

NHS Health Check in promoting dementia risk reduction advice (primary prevention)

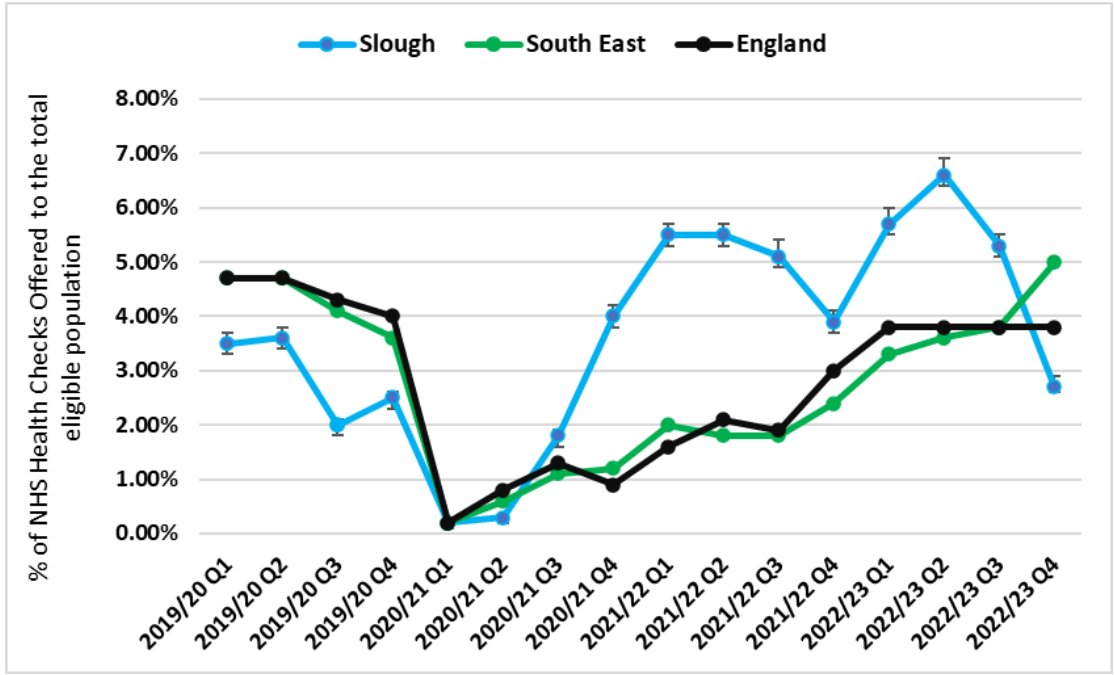
The number of those receiving health checks locally has slightly decreased over the last two quarters, but that could be due to reporting lag.

The NHS Health Checks programme offers all people between the ages of 65-74 years, that are receiving a health check, information and advice on dementia.

- Overall, Slough is offering more health checks to the eligible population compared to SE and England over the last two years.
- NHS Health Checks participants are made aware of the signs and symptoms of dementia and signposted to memory services if appropriate.

According to the Solution for Health (S4H) commissioning NHS HC locally: all residents over 65 (tot.174) receiving a health check locally for 2022/23 were offered dementia risk advice.

The data suggest that **there is some form of discrepancy between those eligible residents receiving a Health Check annually and those also receiving advice on dementia**.



Source: OHID/PHE Fingertips

Young Onset Dementia – Dementia UK facts & figures

When a person develops dementia before the age of 65, this is known as 'young onset dementia (YOD)'.

Like all people with dementia, younger people may experience a wide range of symptoms, especially on the early stages of dementia. However, they are likely to need different support to older people. Mild cognitive impairment (MCI) and mild dementia are forms of early dementia.

Unlike dementia, symptoms of MCI may not get in the way of a person's day-to-day life. For some people with MCI, their memory and thinking problems stay the same, but for others they may get worse over time. There are many causes of MCI, some of which are more common in younger people, including:

- Depression, stress, and anxiety | Vitamin deficiencies | Thyroid disorders | Autoimmune conditions | Infections | Side effects from medication | Sleep disorders like sleep apnoea | Early stages of Alzheimer's disease or another type of dementia.

Prevalence of young onset dementia

- An estimated **7.5%** or 70,800 of the estimated 944,000 people living with dementia in the UK are living with YOD where symptoms occurred under the age of 65. The estimated prevalence figure for YOD, where diagnosis was between age 30-64, is 92 per 100,000 of the general population.
- Prevalence rates for young onset dementia in minority ethnic communities are higher than for the population as a whole. People from these backgrounds are also less likely to receive a diagnosis or support.
- People with a learning disability are at greater risk of developing dementia at a younger age. Studies have shown that one in ten develop young onset Alzheimer's disease between the age of 50 to 65.

Young onset dementia: facts and figures - Dementia UK | Young onset dementia - Alzheimer's Research UK (alzheimersresearchuk.org)

Young Onset Dementia (YOD) and our local service

Dementia HNA (2018-19) identified an increase in the referrals of young people aged under 65, to the memory services, with a confirmed YOD diagnosis.

The recommendations from this work led to reduced timeframe for referrals to a provisional diagnosis within 6 weeks from 12 weeks that was prior to that work locally.

YOD locally: Those under 64 years old, diagnosed with YOD, and their carers, are known to be at risk of 'falling through the net' of health and social care services due to:

- Missed diagnosis as comparative data on currently diagnosed dementia (all ages) in relation to other diseases that have a strong link to dementia, depicts a vast difference in numbers.
- Prevalence data on YOD for Slough are very limited. The latest (2020) figures suggest that more males aged 30-64 are diagnosed with YOD compared to their female counterparts.
- Referrals: The local data suggest an increase for people aged under 65 referred to the Memory clinic with a confirmed diagnosis of YOD.[1] That's a clear indication on the YOD services and the need for better care coordination in Slough.

1. Slough Market Position Statement Slough

Dementia care pathway and patient journey in Slough (diagnosing well)

Alzheimer's Society measured user experience to map out the needs of people affected by dementia and create large-scale solutions.

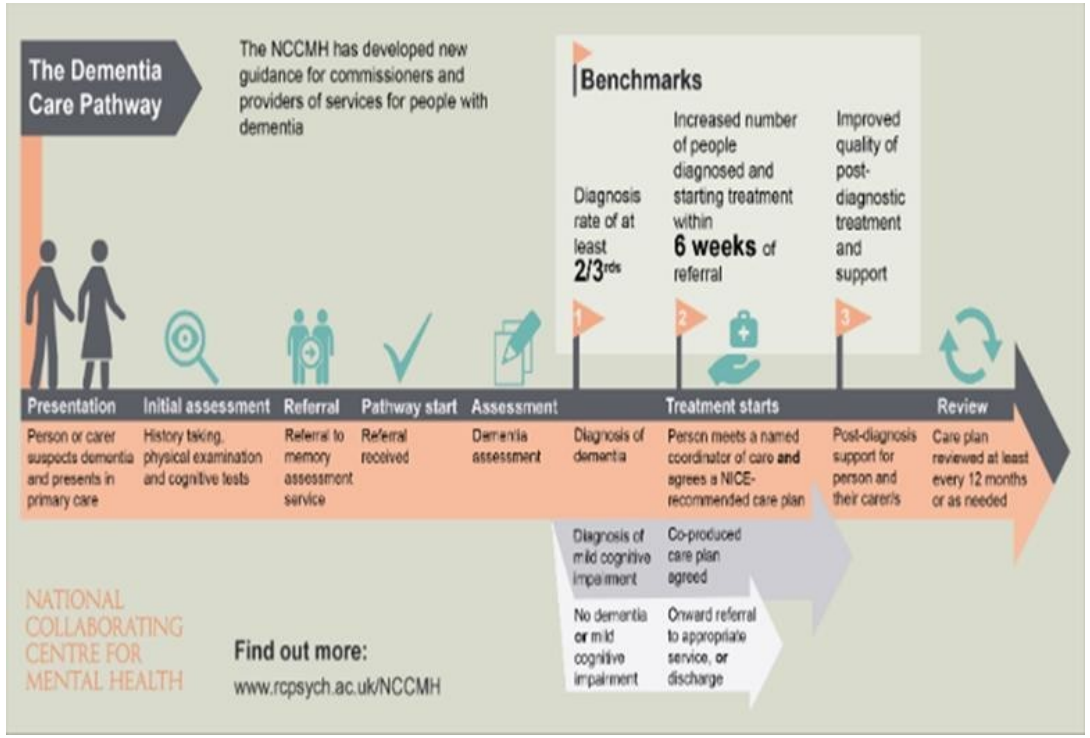
As part of developing the local Dementia HNA we need to better understand and improve dementia patient journey that will include:

- **The map of services and key stakeholders locally**, and
- **Understand their roles/responsibilities** including their relationships aiming to improve support and quality of care

Social services support for dementia

The adult social services can help affected individual with personal care and day-to-day activities.

Social services can also give affected individuals information about local services and support, much of which is provided by charities such as the Alzheimer's Society and Age UK.



Source: Dementia pathway (Royal college of psychiatrists)

1. Mapping diagnosis journey - Alzheimers society

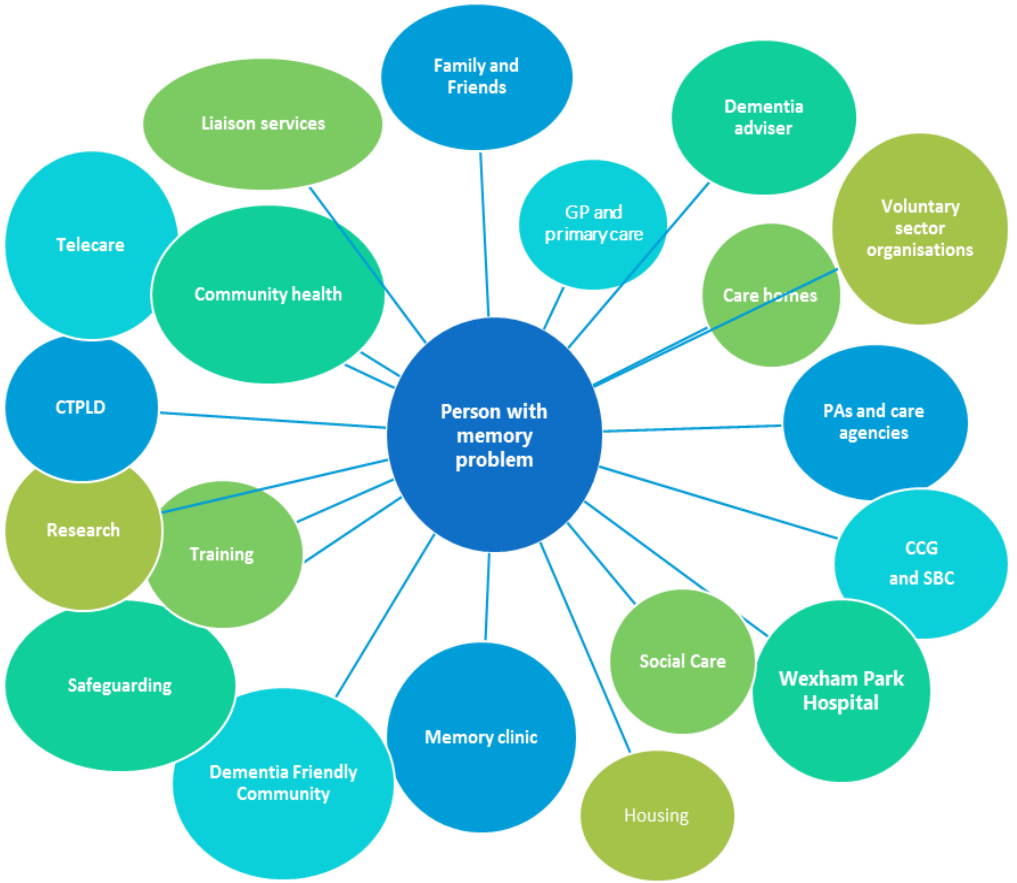
There are several dementia care services in Slough supporting the local dementia care pathway

Local Dementia Care Groups

- Dementia Subgroup (PH and OPMH team joint working to develop a local dementia action plan)
- Memory clinic/Older people mental health services (Dementia Care Advisors)
- Adult Social Care (Case managers)
- BHFT
- GP Practices
- Care Settings

Other Identified local services with potential to contribution to the dementia model/pathway

- Alzheimer's Society / Alzheimer's Dementia Support 'ADS'
- Dementia Action Alliance (DAA)
- Younger People with Dementia (YPWD)
- Telecare under Adult Social Care
- Care UK – Support with information and advice
- Slough Libraries (they offer venues for various activities)



Provision and services were identified to be integrated into the local dementia pathway (local provision)

Slough Memory Service
- MC nurses (3.5 FTE)
- Manager (0.5 FTE)
- Psychologist (1)
- Carers lead (1) AP-1, research facilitator (0.4)
- Consultant x2 (3 sessions pw)
- Admin (2 FTE)
- Dementia advisor (0.8)
- SLT (0.3), OT (0.2), SW (0.1)

Slough Memory Service, Alzheimer's Society and other local providers / services need to be identified locally as they form part of and should be integrated into the pathway (the focus of the 2nd phase).

These and other services should be mapped onto and implemented across the stages of the Well Pathway for Dementia.

The Alzheimer's Society (AS) offer

- AS have local services across the whole of Berkshire. Across East Berkshire, they have 3 voluntary funded Dementia Advisers who can provide dementia support.
- They also run 'Singing for the brain' groups and 'Dementia Voice Involvement' groups.
- AS also provide national services: Dementia Support Line, Talking Point online forum. They offer a range of Publications, Companion Calls Telephone Befriending, external training – that are all available to Slough residents.
- In partnership with the Windsor and Maidenhead Memory Clinic, AS's local dementia advisers delivered a Living well With Dementia Course, which provided information for people with a diagnosis of dementia. There is also potential for a course for carers the 'Careers Information and Support Programme' which could be a beneficial service.
- Alzheimer's Society have a training offer, which could support integration by increasing awareness of dementia across services in Slough.

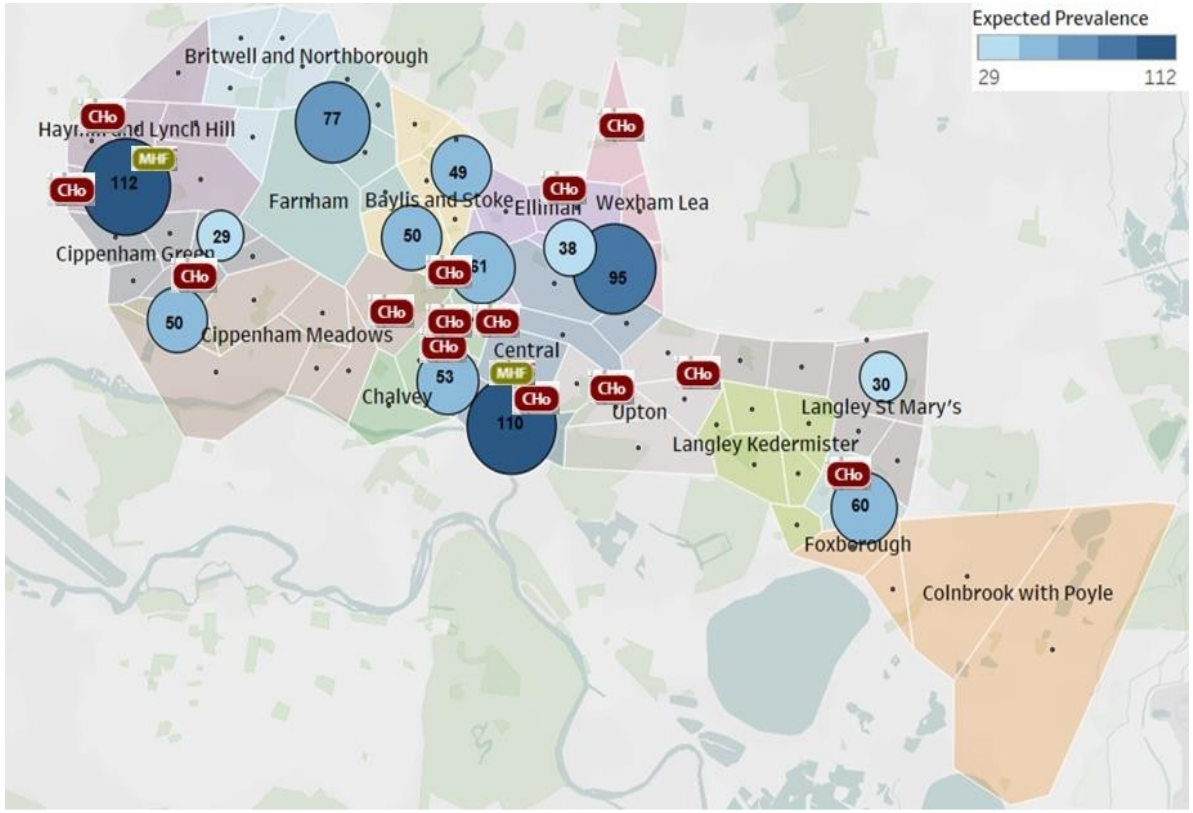
Specialist dementia care homes in Slough (tertiary prevention)

Slough has 16 care homes (CHs) that provide different type of services and 7 of them offer specific care for people with dementia.

- **There is a real shortage of CHs / providers for younger people or people with challenging behaviour.**
- **The existing CHs in Slough are not equipped for this cohort, so we often have long delays in hospital while we try to source an appropriate placement.**

Applegarth Care Home	OP
Common Road	LDA, YA
Forget Me Not Residential Care Home	OP, D
Respond Adult Respite Service	LDA
Langley Haven Care Home	OP, D
Seymour House	LDA
Lavender Court	LDA
Stoke House	PD, LDA, YA
Reach LTD	OP, LDA
Oxford House Nursing Home	OP, D
REACH Lower Cippenham Lane	OP, LDA
REACH Upton Court Road	OP, LDA
Oak House	OP, D, PD, LDA, MH
Windsor Care Centre	D, PD
Salt Hill Care Centre	OP, D, PD, LDA, MH
Windmill Care Centre	D, OP

Care home locations and dementia prevalence map for Slough



Service User Bands: OP Older people (65+) D Dementia PD Physical disability LDA Learning disability, autism MH Mental health SI Sensory impairment YA Younger adults AD People who misuse alcohol or drugs

Contents

Public health interventions offer benefits in delaying the disease onset while improving the severity of dementia symptoms

Risk factors and prevention: Although age is the strongest unmodifiable risk factor for dementia, it is not an inevitable consequence of biological ageing. Further, dementia does not exclusively affect older people as young onset dementia accounts for up to 9% of cases. There is evidence to suggest that people can reduce their risk of cognitive decline and dementia by being physically active, not smoking, avoiding harmful use of alcohol, controlling their weight, eating a healthy diet, and maintaining healthy blood pressure, cholesterol and blood sugar levels. Additional risk factors include depression, social isolation, low educational attainment, cognitive inactivity and air pollution. [1]

- **Exercising in mid-life:** Combining the results from many studies shows that regular exercise can significantly reduce the risk of developing dementia by about 30 per cent. For Alzheimer's disease specifically, the risk was reduced by 45 per cent. [2]
- **Social engagement:** Research shows that loneliness and isolation predict cognitive decline and the onset of dementia. The evidence also suggest that social engagement alone predicts cognitive improvement 5 years after being diagnosed with mild cognitive impairment (MCI). [3]
- **Healthy eating**: Diet is an important modifiable risk factor for dementia. Data from a large UK Biobank prospective study (over 60,000 participants), demonstrated that higher adherence to the Mediterranean Diet (MedDiet) was associated with (23%) lower risk of incident all-cause dementia [4].

1. Dementia (who.int)
2. Mediterranean diet adherence is associated with lower dementia risk, independent of genetic predisposition: findings from the UK Biobank prospective cohort study | BMC Medicine |
3. Pre-dementia: Social engagement may help restore cognition (medicalnewstoday.com)
4. Physical exercise and dementia | Alzheimer's Society

Long COVID: the impact on cognitive functions and older people

- In addition to other pre-existing health conditions, **people infected with COVID-19 were at higher risk of developing dementia**, while individuals with dementia have almost twice the risk for COVID-19.
- **People with dementia had a rate of death involving COVID-19 four time higher than people without dementia**
- **Long COVID (LC) encompasses a suite of long-term symptoms that commonly include fatigue, shortness of breath, and so-called brain fog,** along with many others**.**

- Adults: The evidence suggest that a degree of cognitive difficulty is especially common to those affected by LC (US study 2022). [1]
- Older people: The findings from a cohort study of 1438 COVID-19 survivors (60 years and older) who were discharged from COVID-19–designated hospitals in Wuhan, China, the incidence of cognitive impairment was higher among COVID-19 survivors. The study suggested that long-term cognitive decline is common after SARS-CoV-2 infection in older people indicating the necessity of evaluating the impact of the COVID-19 pandemic on the future dementia burden worldwide. [2]
- New research reported at the Alzheimer's Association International Conference (AAIC, 2021), found associations between COVID-19 and persistent cognitive deficits, including the acceleration of Alzheimer's disease pathology and symptoms. [3]

1. The Fed - Long COVID, Cognitive Impairment, and the Stalled Decline in Disability Rates (federalreserve.gov)
2. One-Year Trajectory of Cognitive Changes in Older Survivors of COVID-19 in Wuhan, China: A Longitudinal Cohort Study | Coronavirus (COVID-19) | JAMA Neurology | JAMA Network
3. COVID-19 Associated with Long-Term Cognitive Dysfunction, Acceleration of Alzheimer's Symptoms | AAIC 2021

Contents

Dementia is the most feared disease among adults aged over 65

Community & Stakeholder Views

Dementia is the second most feared conditions for adults (aged 18–64 years) after cancer, **and the most feared condition among those aged 65 years and over** (33% of them) [1]

Dementia Carers Count are carrying out a survey into the experiences of people caring for friends and family living with dementia. Their research in 2022 included their first ever nationwide survey of family dementia carers [2]. Through the survey, they found out that:

- **over half of people caring for someone with dementia receive no support**;
- most have never had a carer's assessment, and
- many don't know how to access any help. This is **leading to dementia carers reaching crisis points, one in five on a regular basis**.

This year, they are carrying out a a new survey. They are asking carers to share the specifics of what caring for someone with dementia involves and what they would like help with to cope and to maintain their own physical and mental health. The survey will be open until mid-September 2023. They will use the findings to help ensure that family dementia carers' needs are better understood, and that support provided by adult health and social care services to families living with dementia is designed and delivered with carers' needs in mind.

Monitor update: *Set against the backdrop of over half a million people across the UK taking part in research into the effects of, and treatment for, COVID-19 and the publicity surrounding this research, the Monitor found that:*

- the majority (69%) of UK adults would now consider getting involved in medical research for dementia. This represents a marked increase since Wave 1 (50%).
- By age, the Monitor shows that willingness to get involved in research is highest among those aged 25 – 34 (75%) and lowest among those aged 65+ (57%), where there is arguably the most to learn about the condition. [3]

1. Dementia is the second most feared condition among ... - NCBI National Institutes of Health (.gov)
2. Family Carers Survey 2022 | Dementia Carers Count
3. Monitor Update - DEMENTIA RESEARCHER (nihr.ac.uk) Dementia Attitudes

Contents

Phase 2:
Support the dementia care integration process locally – proposed next steps

Improve awareness and understanding of dementia and its risk factors among our residents. As part of that process: (i) refresh the current local dementia resource pack for our residents (that OPMH and Memory Clinic has produced), and (ii) develop a dementia awareness pack for professionals locally.

Partnership working

- **Engage with OP steering group to support the Dementia Action Plan** that can take forward the key findings of this needs assessment. As part of that, **Support community-based activities** that are accessible and meet the needs of people living with Dementia and their carers.
- **Use connected care to risk profile Slough residents and look at what the preventative offer** in those areas are locally (for e.g. smoking cessation) as well as look to fund other initiatives locally (for e.g. the community pharmacy offer). We should also explore what else is that being offered to our residents known to be at risk of developing dementia.
- **Work more effectively with providers** and in collaboration with our local GP practices and the Slough Memory Clinic to coordinate their efforts in improving both (i) diagnosis rates of dementia (including those with a young onset of dementia), and (ii) their coding system.

Older People Action Plan (reference to Dementia)

▪ To support the dementia care model/pathway locally. ▪ Continuing to work in close collaboration with all key partners and stakeholders locally is important as part of monitoring and evaluating our work.	▪ A dementia care task & finish group is proposed to take forward this work and develop a standalone Dementia Action Plan for Slough. ▪ Dementia is the pillar of this strategy. Linked to priority 1 & 4.	▪ A robust Dementia Action Plan by January 2025 as part of a preventative approach to minimising or delaying Dementia and tackling social isolation linked to priority 1. ▪ Measures: A range of associated KPIs in line with the Public Health Prevention Needs Assessment.

- Work in partnership towards making Slough a more **dementia friendly borough** and be recognised as a dementia friendly community.

Summary

Key Message: Dementia is a progressive condition, severe enough to interfere with daily life. It is one of the leading causes of death in the UK and a condition with a large impact to those affected as well as healthcare services. For Slough, the focus should be on developing and implementing a preventative dementia life-course approach and investing in our partnership working with all service providers.

- **The disease burden**: The condition affects around 944,000 people across the UK (2021) and the numbers are set to rise to over a 1.1 million by 2030. The average annual cost for a person with dementia is estimated at £32,250. The local dementia healthcare cost is projected to increase by over 70% on 2030 as compared to 2019, mainly due to a significant increase of social care costs. This projected increase could derive from those diagnosed at a later stage of the condition as well as those unknown to dementia care services.
- **Levels of need**: The current levels of dementia prevalence locally are still low (compared to SE and England average), partly due to our demographic make up (with a younger population), but with the level of awareness and access to services also playing a part. The expected dementia prevalence is estimated to be around 40% higher than the recorded prevalence and is increasing among older adults. The dementia emergency admissions in Slough are higher than both SE and England average – an indication of a higher need for dementia acute care services.
- **Tackling modifiable risk factors for dementia**: Several modifiable risks have been identified at different stages of life with some known as ‘early-life risks’, such as less education, affecting cognitive reserve; while midlife, and later-life risk factors influencing both the cognitive reserve and trigger neuropathological developments. In Slough some of the main risk factors (including smoking, physical inactivity, excess drinking and poor dietary habits) are more prevalent and of real concern for the future.
- **Dementia care services locally**. These exist, however local stakeholders view is that we need more services in Slough and there is a need to invest more on increasing both the capacity and resources. Slough Memory Service, Alzheimer’s Society and other local providers could add more value to our pathway. These and other services can be mapped across the stages of the Well Pathway for Dementia.
- **Proposed next steps**: This needs assessment will serve as a baseline that will inform the 2nd phase (i) supporting the Older People strategy and, (ii) OP steering group and the dementia TFG to implement the action plan with a focus on improving the dementia care for Slough.