



CHAPTER 6: LIVING WITH DEMENTIA

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6 LIVING WITH DEMENTIA

6.1 Introduction and Definition

Dementia is an umbrella term for a range of progressive conditions that affect the brain. Individual symptoms differ but tend to involve decline in memory, reasoning, and communication skills which is further exacerbated by loss of daily functional skills to manage daily living (Dementia UK, 2021). A significant number of people living with dementia will also develop "behavioural and psychological symptoms of dementia (BPSD)" which include:

- Increased agitation
- Delusions
- Anxiety
- Wandering
- Hallucinations
- Aggression

Around 225,000 people will develop dementia each year and one in six people over the age of 80 has dementia costing the UK £26 billion a year (Alzheimer's Society, 2014). Numbers are projected to rise to over one million by 2025 and two million by 2051, resulting in exponential rises in health and social care costs dementia (Alzheimer's Society, 2014). There is increasing recognition that, as people are living longer, the number of older people who will be affected by cognitive decline and dementia is subsequently rising (Prince, et al., 2016).

Dementia can affect a person at any age, but it is more common in people over the age of 65. Young-onset Dementia or Early-onset Dementia affects adults between the ages of 30-64. About 5% to 6% of people with dementia develop symptoms before age 65 (Mayo Clinic, 2022). In 2014, it was estimated that there were 42,325 people in the UK with a diagnosis of young onset dementia, representing around 5% of the 900,000 people living with dementia (Dementia UK, 2022).

Dementia has historically been managed as a mental illness due to the affect the disease has on the brain. More recently, dementia has been recognised as a long-term physical health condition. This allows diagnosis and management to take place within community settings and gives the opportunity for localised care and support, allowing those living with dementia and their carers the option to manage their own condition and improve independence. From a prevention perspective, evidence has shown that prevention is possible through identifying and addressing some of the risk factors and considering the wider determinants of health (Regan, 2016).

6.2 Types of dementia

There are over 200 subtypes of dementia (Dementia UK, 2021). Alzheimer's disease is the most common form of dementia. The proportions of those with different forms of dementia can be broken down as follows (Alzheimer's Society, 2022):

- Alzheimer's disease (50%–75%) which often co-exists with vascular dementia.
- Vascular dementia (up to 20%).

- Dementia with Lewy bodies (10%–15%).
- Frontotemporal dementia (2%).

Individuals may have a combination of several types of dementia called Mixed Dementia (Dementia UK, 2021).

6.3 Risk factors

Some of the risk factors associated with dementia are non-modifiable such as a person's age or gender. Others may be modified and are key for preventive measures to reduce the chances of people developing dementia.

6.3.1 Non-modifiable factors

- **Age:** People living with dementia tend to be over the age of 65. Above this age, a person's risk of developing Alzheimer's disease or Vascular Dementia doubles roughly every five years. Once over the age of 80, there is a one in six chance of developing dementia (Dementia UK, 2022).
- **Ethnicity:** People from some ethnic backgrounds are at higher risk of developing dementia than others. People with South Asian and African or African-Caribbean ethnicities are more likely to develop dementia than White Europeans. This could be attributed to specific underlying health risk factors being more highly prevalent in these groups including stroke, diabetes, hypertension, and cardiovascular disease, as well lifestyle factors including diet, smoking, exercise. They may also be at a higher genetic pre-disposition for dementia (Dementia UK, 2022).
- **Gender:** Dementia affects more women than men. Globally, women living with dementia outnumber men two to one. Women over the age of 65 years are two times more likely to be diagnosed with Alzheimer's compared to men, although vascular dementia is diagnosed in slightly more men than women (Dementia UK, 2022).
- **Genetics:** Rarely Alzheimer's disease can be passed from one generation to another usually affecting people under the age of 65 years (Dementia UK, 2022).
- **Learning Disabilities:** Individuals with learning disabilities, in particular Down's syndrome, have an increased risk of developing dementia (Alzheimer's Society, 2022).

6.3.2 Modifiable risk factors

A report on dementia prevention, intervention, and care outlined twelve potentially modifiable risk factors for dementia shown in Figure 6.1 (Livingston, et al., 2020). Knowledge and understanding of these risk factors can allow for early, targeted interventions to prevent the development and early detection of cases and slow the progression in those already living with dementia. Figure 6.2 (Livingston, et al., 2017) outlines how the 12 risks can be moderated to prevent dementia via a reduction in neuropathological damage and an increase in cognitive reserve.

Figure 6.1: Risk Factors for Dementia life Cycle (Livingston, et al., 2020)

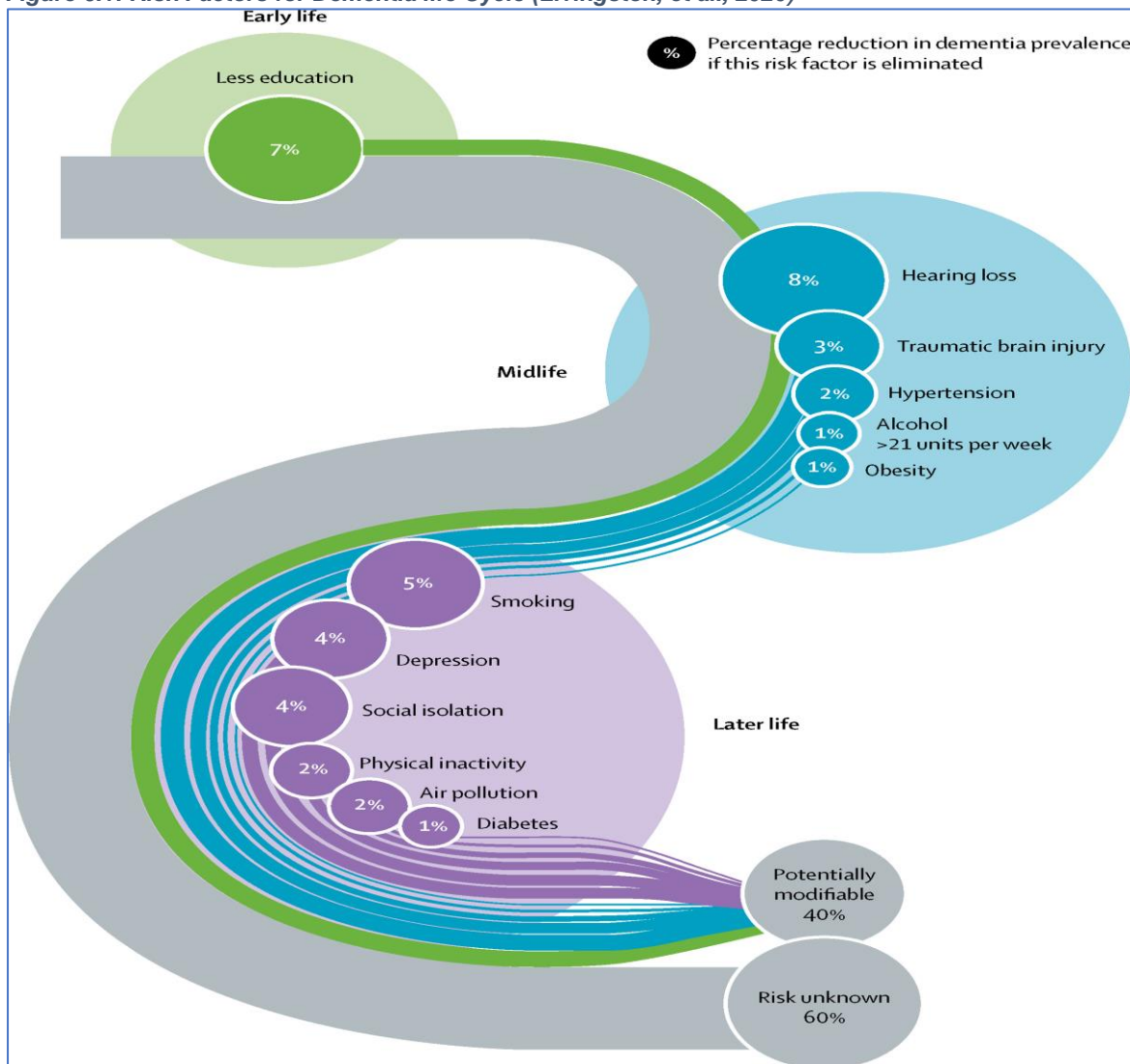
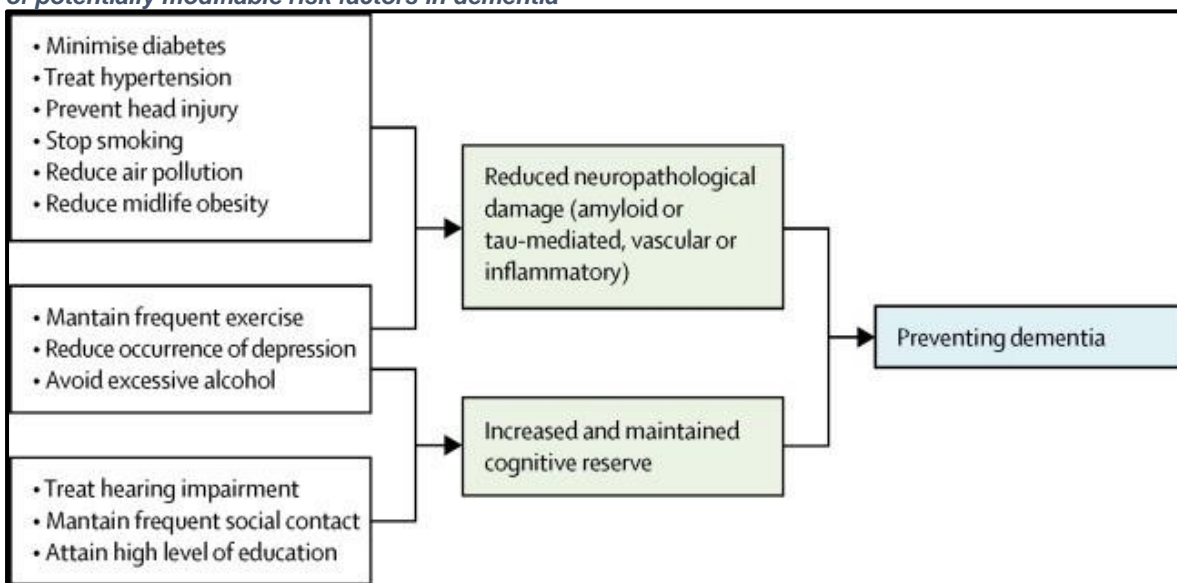


Figure 6.2: Possible brain mechanisms for enhancing or maintaining cognitive reserve and risk reduction of potentially modifiable risk factors in dementia



Source: (Livingston, et al., 2017)

Practical steps that be taken to reduce their dementia risk include:

- Having regular health care checks with GPs and ensuring long-term condition like diabetes or thyroid problems are well managed
- Monitoring blood pressure, weight, and cholesterol levels
- Understanding appropriate medication use and their regular reviews by GPs
- Monitoring diet and weight loss if required
- Eating a healthy and varied diet
- Taking part in regular physical activity
- Taking part in social activity
- Reducing/moderating alcohol intake

6.4 Dementia risk factors in the Wokingham population

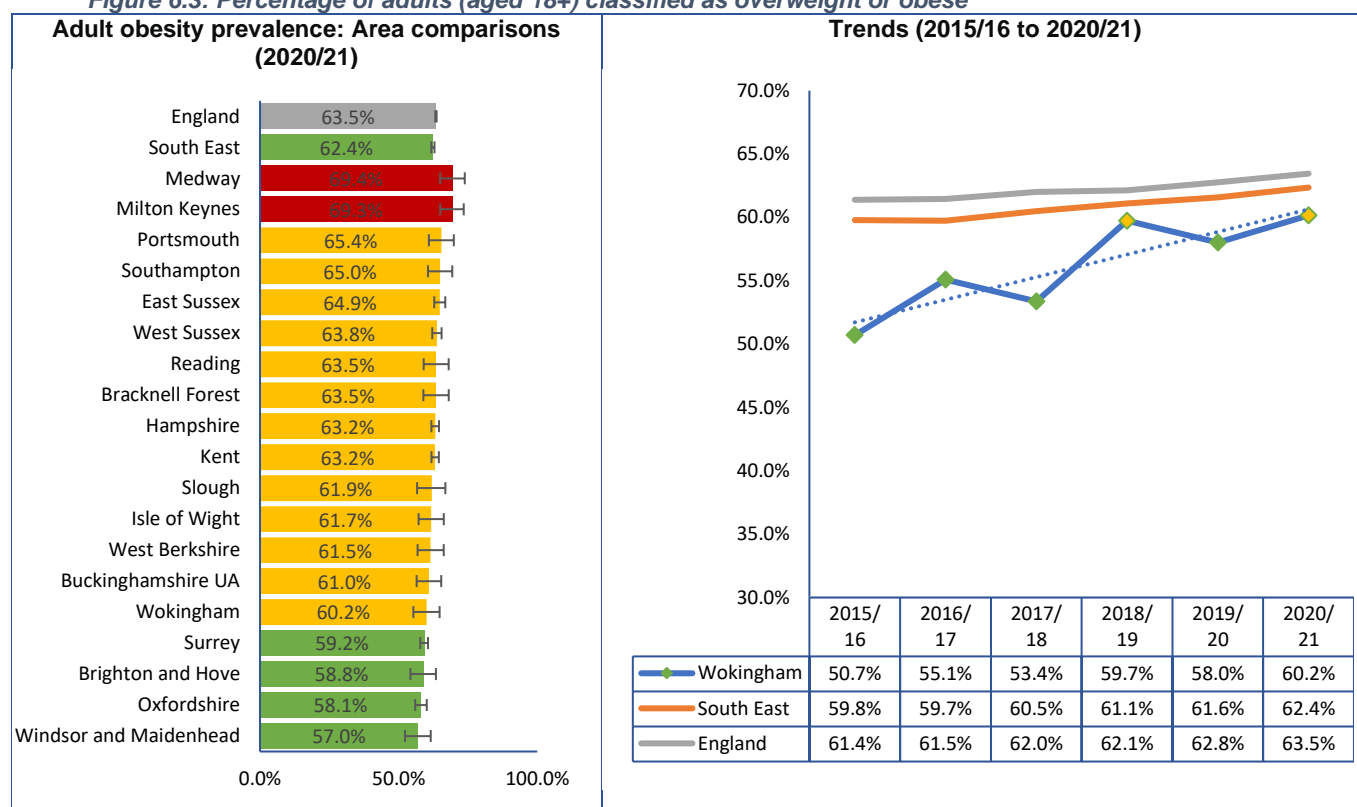
This section provides information on some of the potentially modifiable risk factors.

6.4.1 Lifestyle risk factors

6.4.1.1 Obesity

A 2020 study (Ma, Ajnakina, Steptoe, & Cadar, 2020) has shown increased body weight or abdominal obesity is associated with increased dementia incidence. Obese individuals are 31% more likely to develop dementia compared with people of normal weight while overweight individuals were 27% more likely to develop dementia. Women with central obesity have a 39% greater risk of dementia compared with non-central obese women but there is no link between waistline and dementia in men.

Figure 6.3: Percentage of adults (aged 18+) classified as overweight or obese



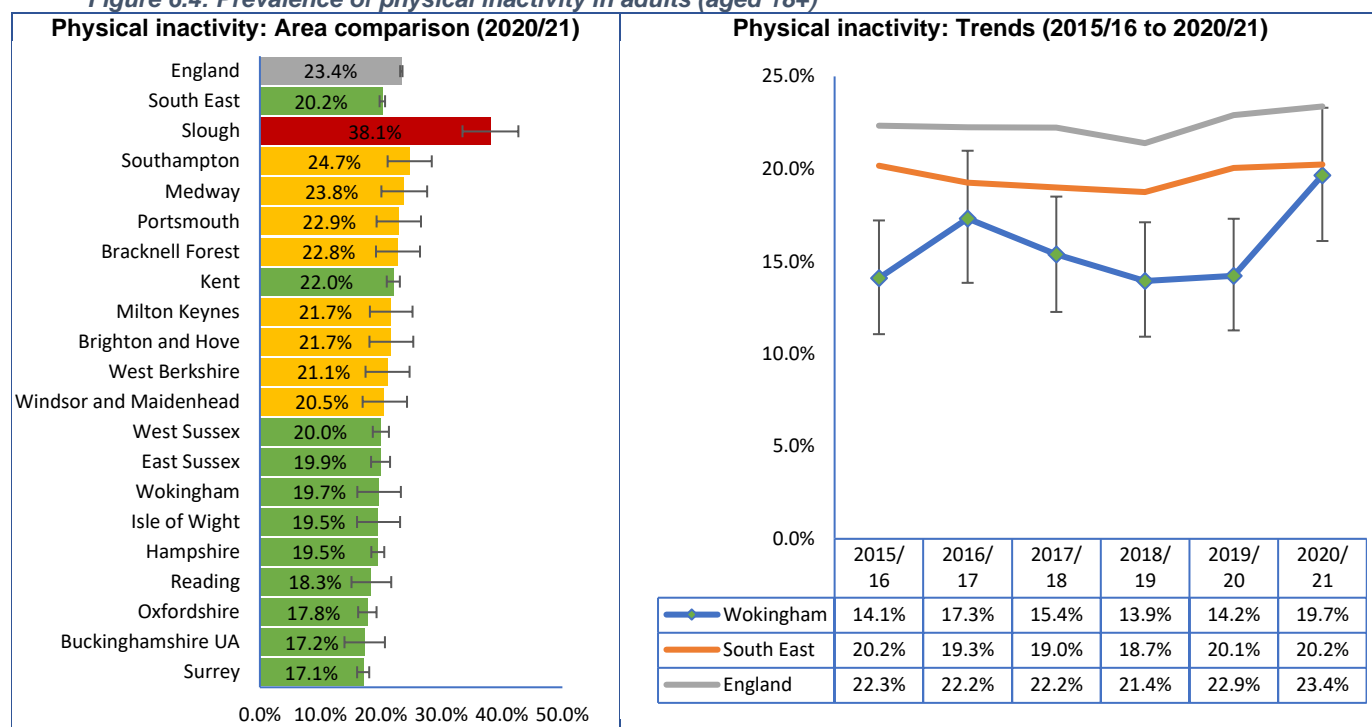
Source: *Dementia Profile* (Office for Health Improvement and Disparities, 2022)

In Wokingham the proportion of adult who are overweight or obese in 2020/21 was 60.2% similar to the England average of 63.5%. However, there has been an increasing trend in recent years leading an increase of 9.5 percentage points increase between 2015/16 and 2020/21 compared with 2.6 and 2.1 percentage point increase in the South East and England respectively (Figure 6.3).

6.4.1.2 Physical activity

Existing evidence shows that regular exercise can significantly reduce the risk of developing dementia by about 30% and for Alzheimer's disease specifically, the risk was reduced by 45% (Alzheimer's Society, 2022). In 2020/21, 19.7% of adults in Wokingham were physically inactive, significantly lower than the national average of 23.4% but similar to the South East average of 20.2%. There has been a year-on-year decline in the prevalence of physical inactivity in Wokingham since 2016/17 but the prevalence rose sharply between 2019/20 and 2020/21 most likely due to the impact of COVID-19 (Figure 6.4).

Figure 6.4: Prevalence of physical inactivity in adults (aged 18+)



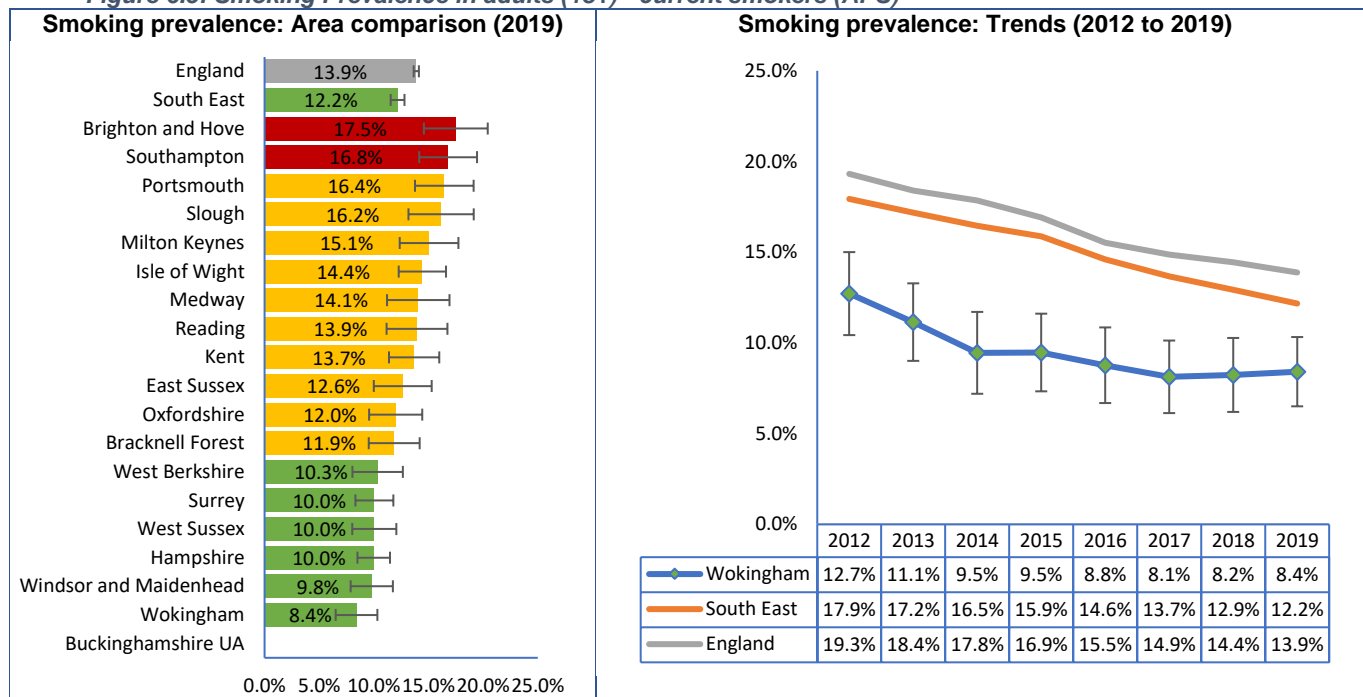
Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

6.4.1.3 Smoking

The WHO estimates that 14% of cases of Alzheimer's disease worldwide are potentially attributable to smoking (World Health Organisation, 2014). Systematic reviews have established that current smokers are 59% to 79% more likely to have Alzheimer's disease and 35% to 78% more likely to have vascular dementia compared with non-smokers (Action on Smoking and Health (ASH), 2019).

Smoking prevalence among Wokingham adults in 2019 was 8.4%, significantly below the South East and England averages of 12.2% and 13.9%. There has been a significant downward trend in the local prevalence in the period between 2012 and 2019, similar to the South East and England trends (Figure 6.5).

Figure 6.5: Smoking Prevalence in adults (18+) - current smokers (APS)

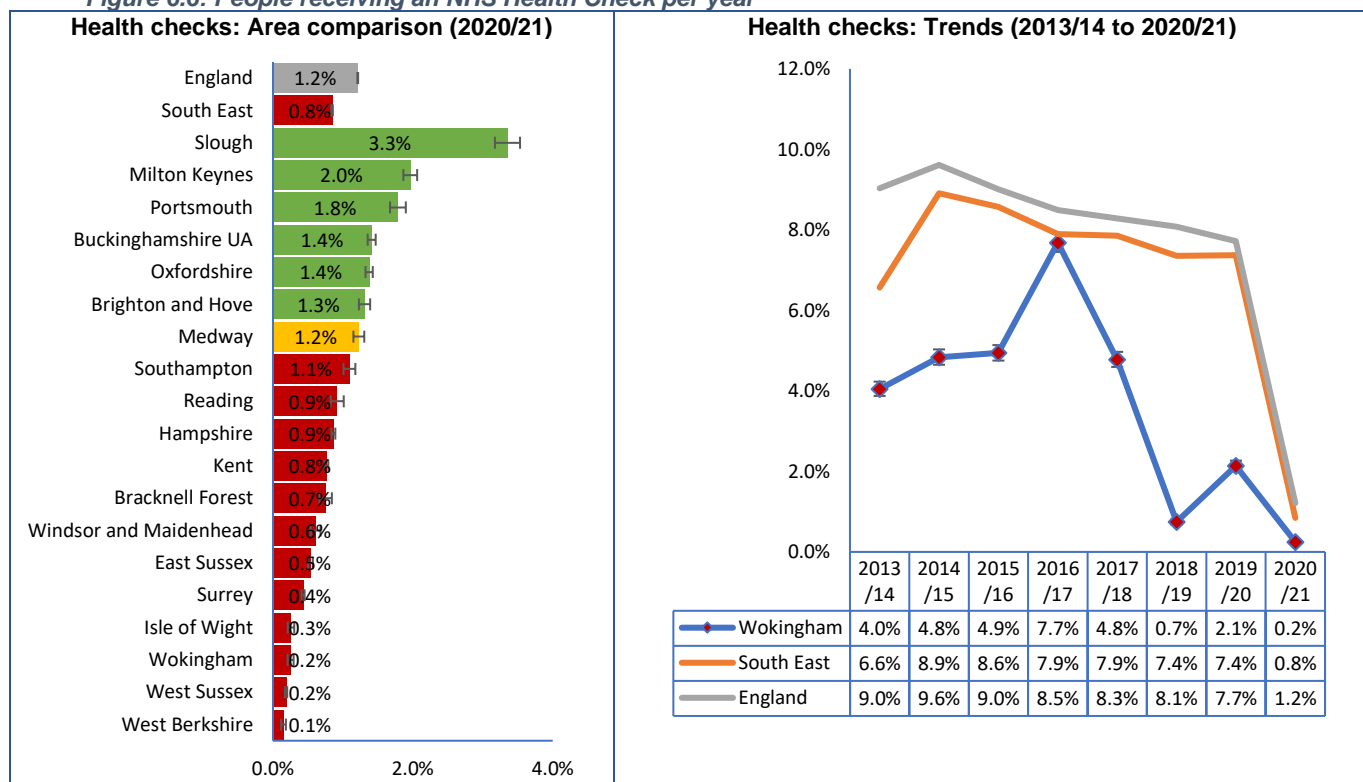


Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

6.4.1.4 NHS Health Checks

The NHS Health Check is a health check-up for adults in England aged 40 to 74. It is designed to identify early signs of stroke, kidney disease, heart disease, type 2 diabetes or dementia and several modifiable dementia risk factors e.g., obesity and smoking (NHS, 2019).

Figure 6.6: People receiving an NHS Health Check per year



Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

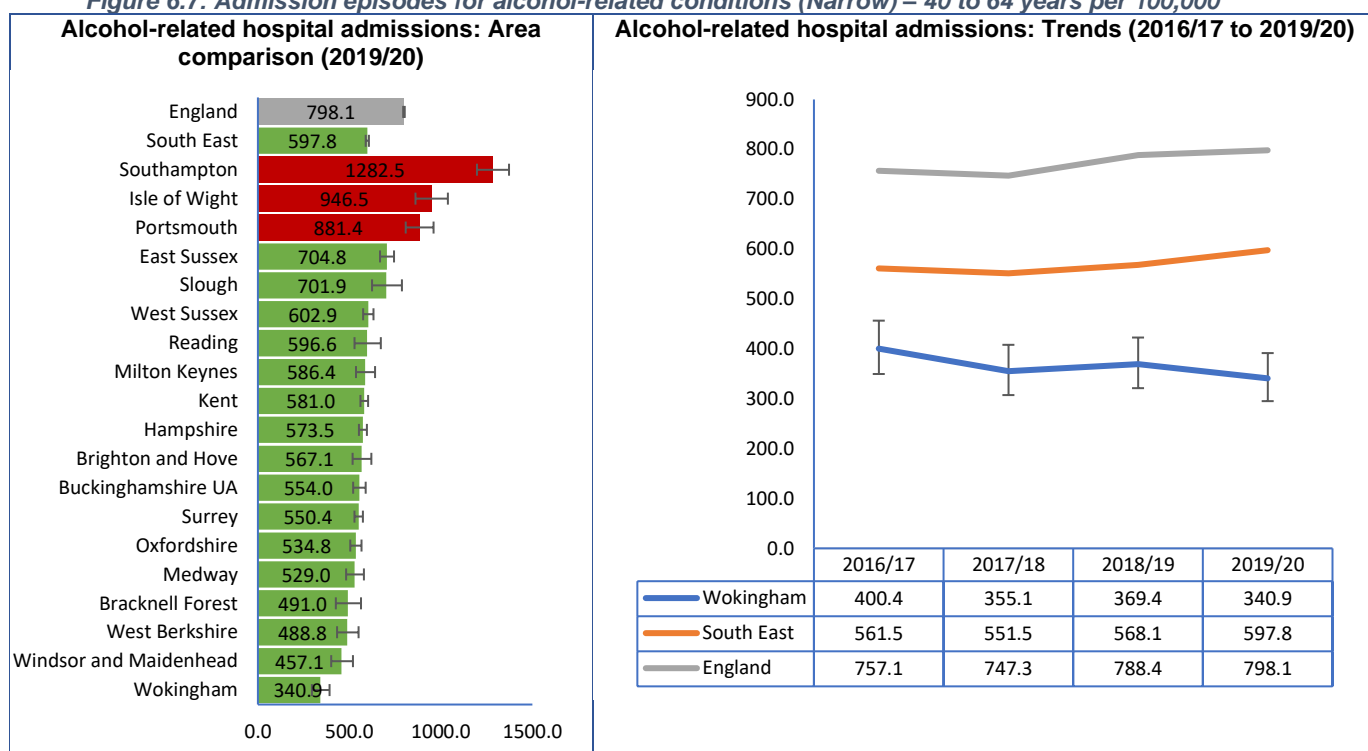
Coverage of the NHS Health Checks among the eligible population in 2020/21 was 0.2% in Wokingham, significantly below South East and England averages of 0.8% and 1.2%. Though this low coverage may be due to the impact of COVID-19, there has been significant decline in the preceding years from the highest coverage of 7.7% over the most recent period in 2016/17 (Figure 6.6).

6.4.1.5 Alcohol admissions

Excessive alcohol consumption over a lengthy period can lead to brain damage and increase the risk of developing dementia but drinking alcohol in moderation has not been conclusively linked to an increased dementia risk, nor has it been shown to offer significant protection against developing dementia (Alzheimer's Society, 2022).

There were no data on excessive alcohol use at the time of writing this needs assessment. Hospital admissions for alcohol-related conditions is used as a proxy for quantifying level of harmful levels of alcohol use. In the South East, Wokingham has the lowest level of episodes of alcohol-related hospital admissions of 340.9 per 100,000 among those aged 40 to 64 years in 2019/20. This was significantly lower than South East and England averages of 597.8 and 798.1 respectively. The rate has been stable in Wokingham between 2016/17 and 2019/20 while there have been increases in the South East and England over the period (Figure 6.7).

Figure 6.7: Admission episodes for alcohol-related conditions (Narrow) – 40 to 64 years per 100,000



Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

Despite overall lower rates of lifestyle risk factors in Wokingham population, we know that even in an affluent area such as Wokingham, inequalities will exist across all the 12 risk potentially modifiable risk factors for developing dementia. For example, smoking in those in routine and manual occupations living in Wokingham is at 13% compared to 5% for the overall adult population.

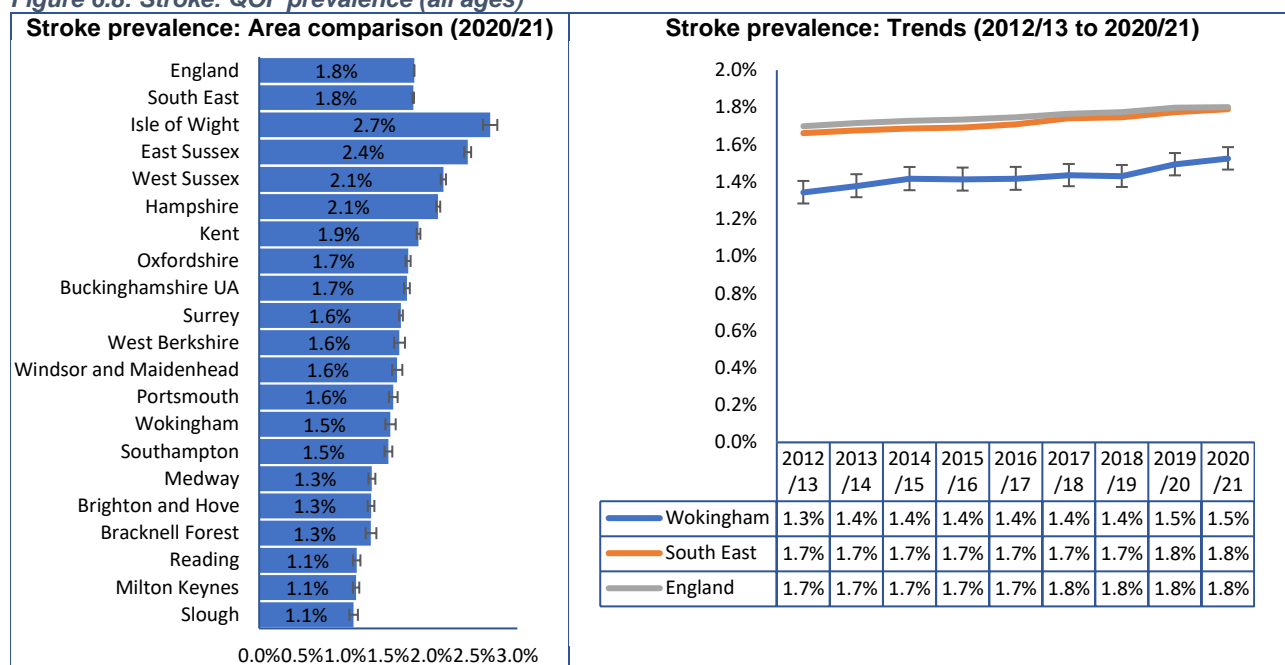
6.4.2 Physical health condition risk factors

6.4.2.1 Stroke

Stroke is a strong, independent, and potentially modifiable risk factor for all-cause dementia. For those with pre-existing stroke the risk for all-cause dementia is 69% higher, while those with new onset of stroke the risk 2.18 times higher than those without stroke (Kuźma, et al., 2018).

Recorded stroke prevalence on GP Quality Outcomes Framework (QOF) data in Woking was 1.5% in 2020/21, significantly lower than South East and England averages of 1.8%. Over recent years (i.e., between 2012/13 and 2020/21) there has been a statistically significant increase in the recorded prevalence from 1.3% in 2012/13 to 1.5% in 2020/21 – similar increases were observed at both regional and national levels (Figure 6.8).

Figure 6.8: Stroke: QOF prevalence (all ages)



Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

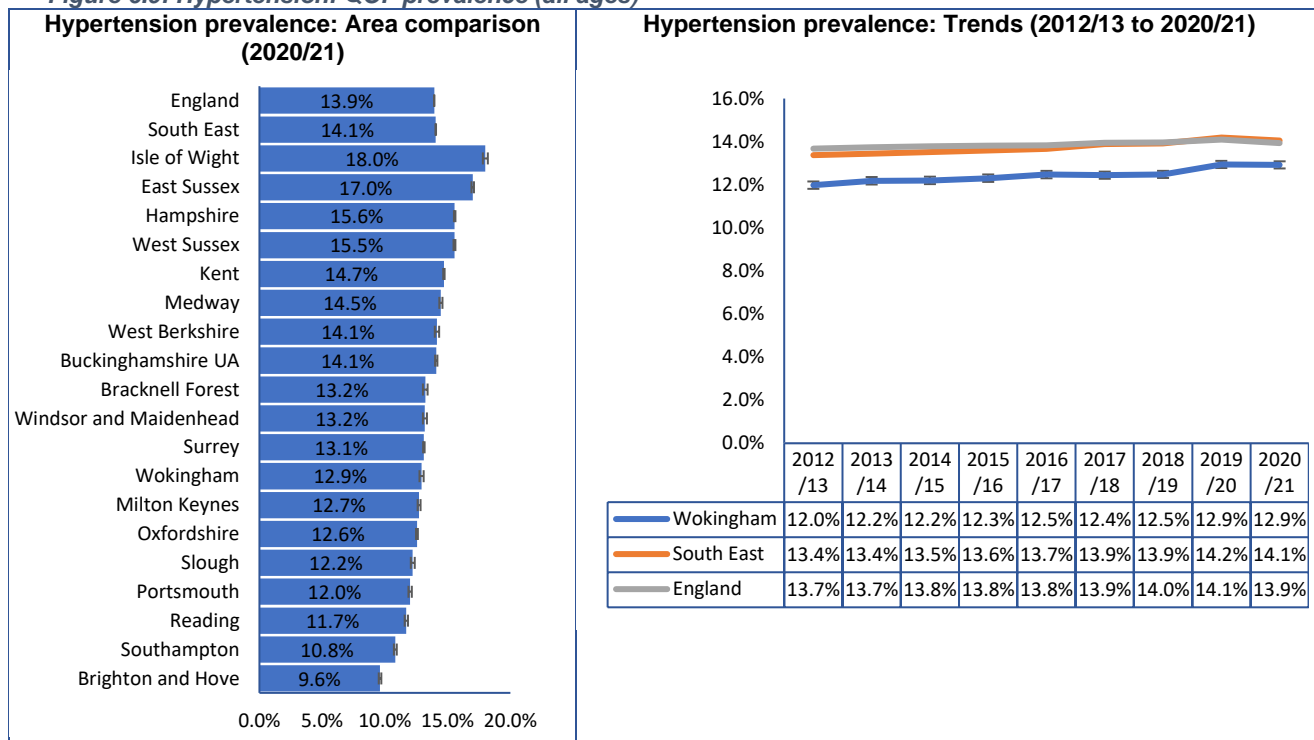
6.4.2.2 Hypertension

Hypertension, particularly midlife hypertension, has been related to a higher risk of cognitive decline and dementia, including Alzheimer disease but these associations are complex and not fully explained. A study found that those with midlife and late-life hypertension are 49% more likely to develop dementia compared with those who have normal blood pressure over 24-year follow-up, and those with midlife hypertension and late-life hypotension (abnormally low blood pressure) are 62% more likely to develop dementia (Sierra, 2020).

Despite this apparent link between dementia (particularly for vascular dementia) and hypertension, the results from randomised controlled trials into the effectiveness of lowering blood pressure in preventing dementia have been inconclusive (Alzheimer's Society, 2022) (Nagai, Hoshida, & Kario, 2010).

Recorded hypertension prevalence on QOF data in Wokingham was 12.9% in 2020/21, significantly lower than South East and England averages of 14.1% and 13.9% respectively. Between 2012/13 and 2020/21, Wokingham has seen a statistically significant increase in hypertension prevalence of 0.9 percentage points – similar patterns were observed at both national and regional levels (Figure 6.9).

Figure 6.9: Hypertension: QOF prevalence (all ages)



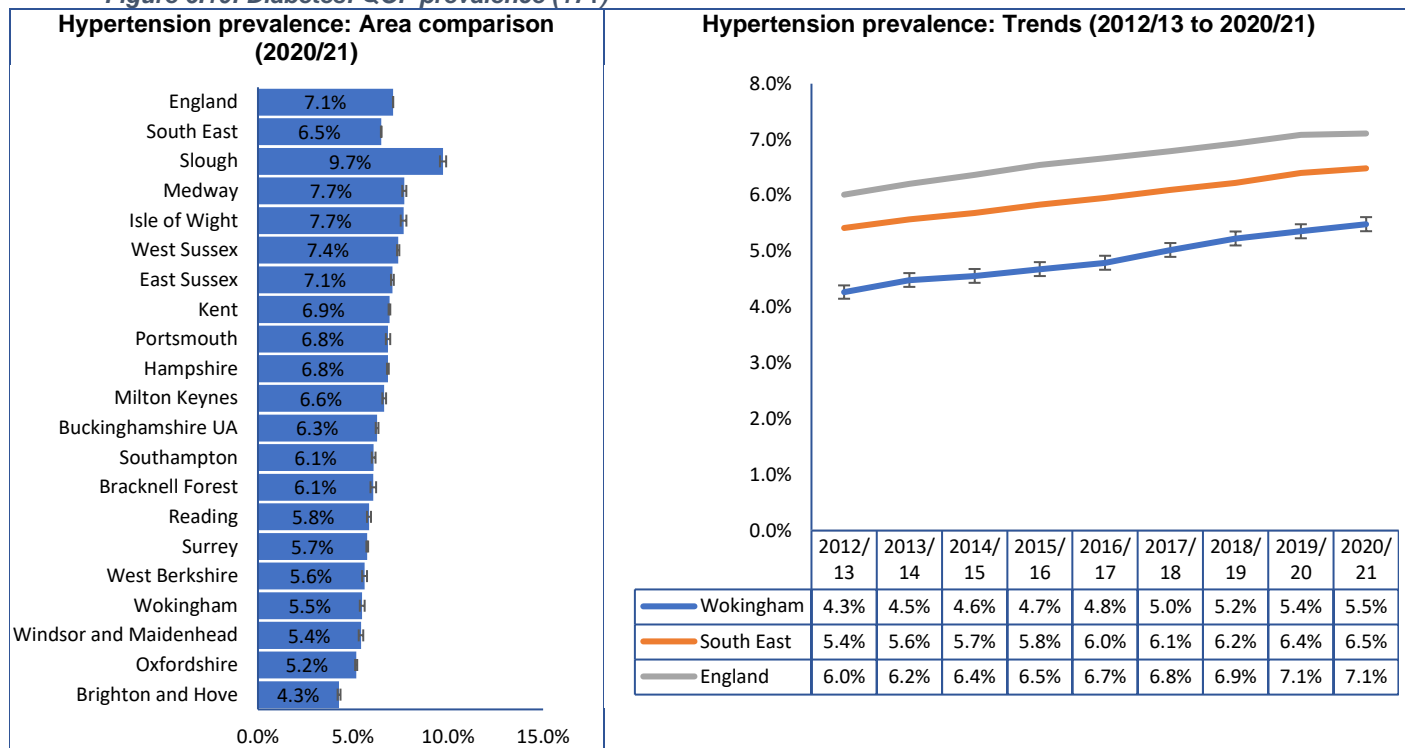
Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

6.4.2.3 Diabetes

Those with diabetes have a higher risk of developing dementia. A systematic review showed that those with diabetes are 73% more likely to develop any type of dementia, 56% more likely to develop Alzheimer’s disease and 2.27 times more likely to develop vascular dementia compared with those who do not have diabetes (Gudala, Bansal, Schifano, & Bhansali, 2013).

Recorded prevalence of diabetes among those aged 17 years or older in Wokingham was 5.5% in 2020/21, significantly lower than South East and National averages of 6.5% and 7.1% respectively. Between 2012/13 and 2020/21, there has been a statistically significant increase in the prevalence by 1.2 percentage points – similar patterns were observed at regional and national levels (Figure 6.10).

Figure 6.10: Diabetes: QOF prevalence (17+)

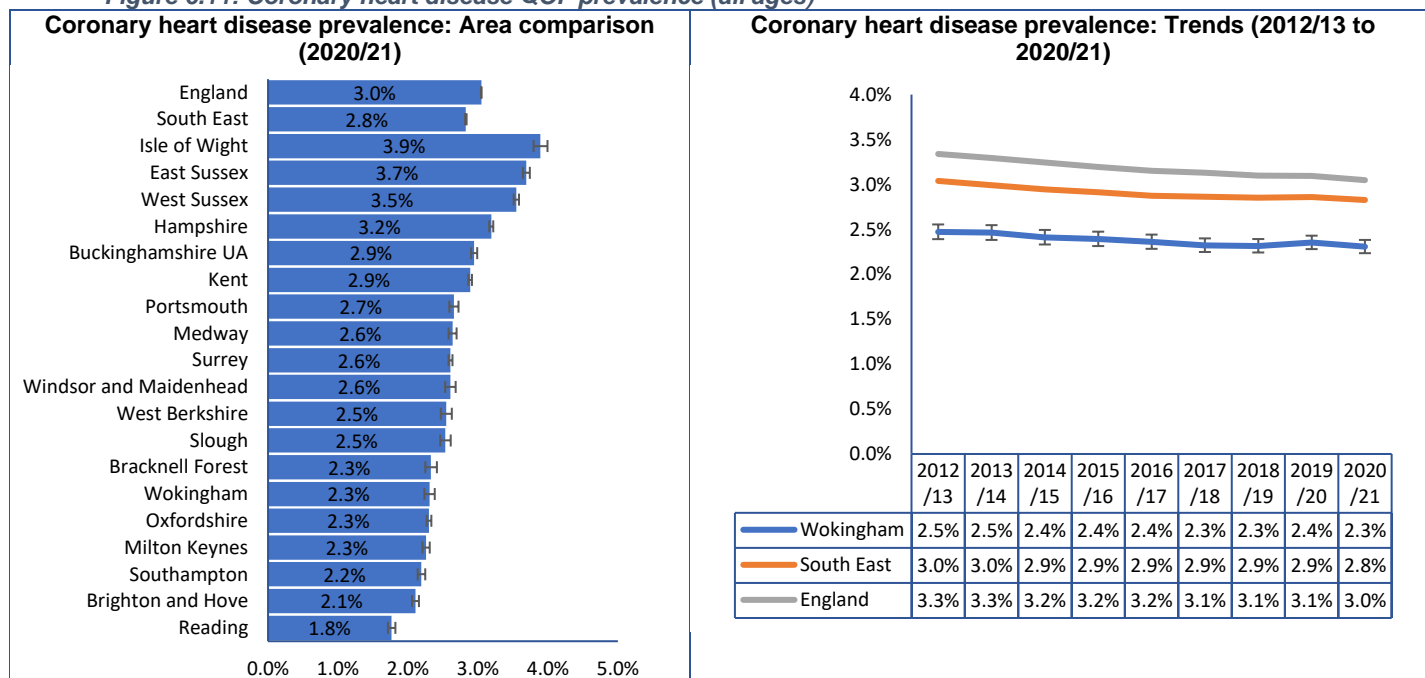


Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

6.4.2.4 Coronary heart disease (CHD)

A systematic review has found a history of CHD to be associated with a 27% increased risk of dementia (Wolters, et al., 2018).

Figure 6.11: Coronary heart disease QOF prevalence (all ages)



Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

Recorded prevalence of CHD among Wokingham residents was 2.3% in 2020/21, significantly lower than South East and England averages of 2.8% and 3.0% respectively. Though there was small reduction of 0.2 percentage points between

2012/13 and 2020/21, this was not statistically significant – similar patterns were apparent at regional and national levels (Figure 6.11).

6.4.3 Mental health risk factors

6.4.3.1 Schizophrenia

A systematic review found that people with schizophrenia are 2.3 times more likely to develop dementia compared with those without schizophrenia than those without (Cai & Huang, 2018). There are no local data on the prevalence of schizophrenia but the chapter on Severe Mental Illness provides an estimated prevalence based on the 2014 Adult Psychiatric Morbidity Survey (APMS).

6.4.3.2 Depression

Depression commonly occurs in individuals with cognitive impairment and dementia. Although some studies have found that depression coincides with or follows the onset of dementia in older adults, most studies including several meta-analyses have concluded that depression precedes dementia and is associated with the risk of developing cognitive impairment or dementia (Barnes, et al., 2012).

A systematic review found that depression is associated with 90% to 2 times increase in the risk of developing dementia (Ownby, Crocco, Acevedo, John, & Loewenstein, 2006). An American study found an increased risk of 19% for midlife depressive symptoms, 72% for late-life symptoms, and 77% for both. Those with late-life depressive symptoms had a 2-fold increase in Alzheimer's disease risk while those with midlife and late-life symptoms had a 3.5-fold increase in vascular dementia risk (Barnes, et al., 2012).

Details of local dementia prevalence can be found in the chapter on Common Mental Health Disorders.

6.4.3.3 Bipolar disorder

A systematic review found that a history of bipolar disorder significantly increases the risk of diagnosis of dementia by 2.36 times (Diniz, et al., 2017).

There are no local data on the prevalence of bipolar disorder but the chapter on Severe Mental Illness provides an estimated prevalence based on the 2014 Adult Psychiatric Morbidity Survey (APMS).

6.5 Dementia prevalence

It is estimated that in 2019, there were almost 885,000 older people (aged 65 years and over) living with dementia in the UK. By 2040 this number is expected to increase to almost 1.6 million as life expectancy is increasing and the main risk factor for dementia is ageing. The number of people aged 65–74 years in the UK will increase by 20% between 2019 and 2040, and the number of people aged 85 years and over will increase by 114% (National Institute for Health and Care Excellence, 2021).

The prevalence rate of dementia among older people in the UK is estimated to be 7.1%. The consensus estimates of population prevalence of late-onset dementia (Prince, et al., 2014) are outlined below:

- 0.9% for those aged 60–64 years.
- 1.7% for those aged 65–69 years.
- 3.0% for those aged 70–74 years.
- 6.0% for those aged 75–79 years.
- 11.1% for those aged 80–84 years.
- 18.3% for those aged 85–89 years.
- 29.9% for those aged 90–94 years.
- 41.1% for those aged 95 years and over.

Of people living in the UK with dementia, it is estimated that (National Institute for Health and Care Excellence, 2021):

- 127,00 have mild dementia.
- 246,000 have moderate dementia.
- 511,000 have severe dementia.
- 1 in 20 are aged under 65 years.

Using the consensus estimates of population prevalence (Prince, et al., 2014) and the ONS 2020 mid-year population estimates, it is estimated 2,250 people aged 65 years or older in Wokingham were living with dementia in 2020, which was equivalent 7.4% (95% confidence interval 7.1% -7.7%) of the population in that age group. This may be an underestimate as the prevalence of many of the risk factors (e.g., stroke, hypertension, diabetes, and obesity) have been increasing.

6.5.1 Recorded dementia prevalence in Wokingham

About 29–76% of people with dementia or probable dementia in primary care are estimated to be undiagnosed (National Institute for Health and Care Excellence, 2021).

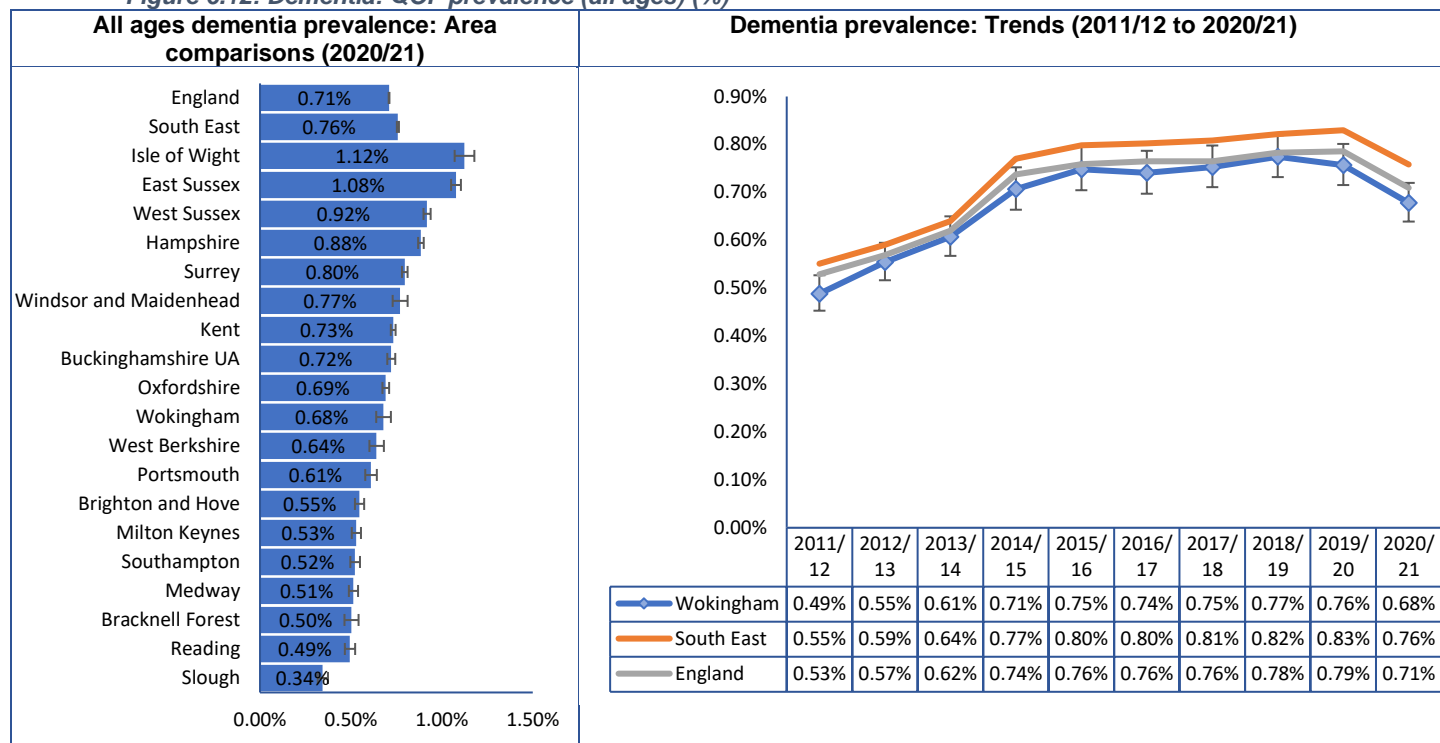
In Wokingham, recorded all-age dementia prevalence for patients on GP Practice registers (QOF data) was 0.68% in 2020/21, lower than the South East average of 0.76% but similar the England average of 0.71%. Overall, there has been a statistically significant increase in the prevalence between 2011/12 and 2020/21 in Wokingham though there was a decrease between 2019/20 and 2020/21 most likely due to the impact of COVID-19. Similar patterns were observed at both regional and national levels (Figure 6.12).

Among individuals of all ages registered with Wokingham GP practices, 0.66%¹ were recorded as having a dementia diagnosis in 2020/21, significantly higher than the prevalence across Berkshire West CCG GP Practices of 0.59%. Wargrave Practice had the highest rate of 1.52%, which was significantly higher than Wokingham and Berkshire West CCG GP Practice averages, while Burma Hill had the lowest rate of 0.16%, significantly lower than the Wokingham and Berkshire West CCG averages (Figure 6.13). No specific inferences can be made relating to the variation across practices as crude dementia prevalence rate is significantly

¹ Some Wokingham residents are registered with GPs outside the borough and some from outside the borough are registered with Wokingham GPs hence the slight difference in the prevalence figure.

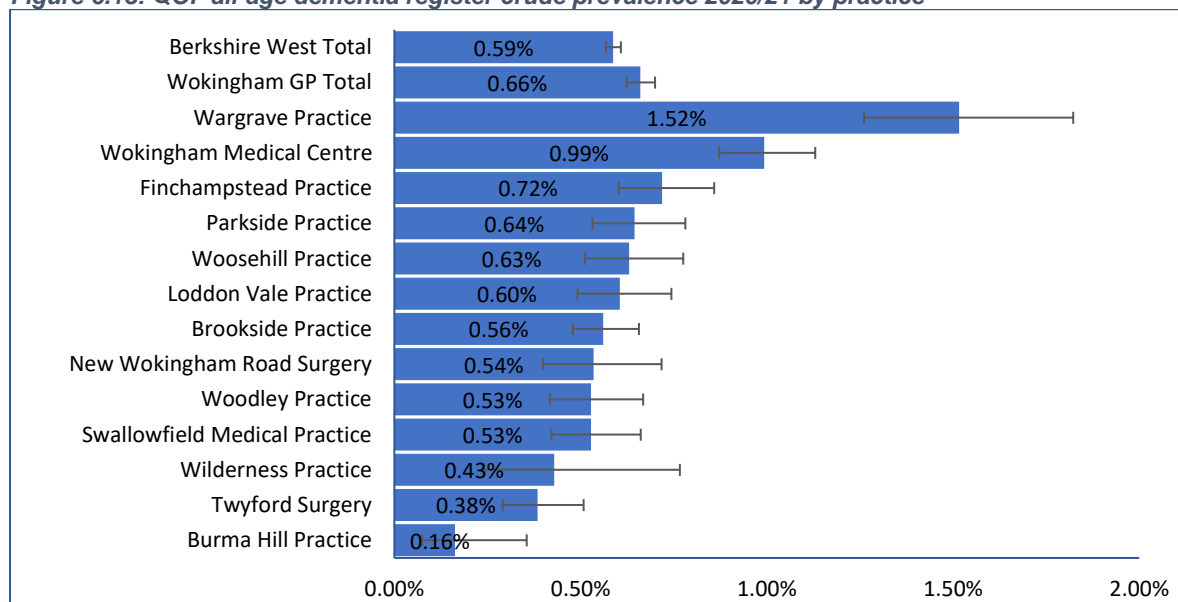
influenced by age, with practices with older age populations tending to record higher prevalence rates.

Figure 6.12: Dementia: QOF prevalence (all ages) (%)



Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

Figure 6.13: QOF all-age dementia register crude prevalence 2020/21 by practice

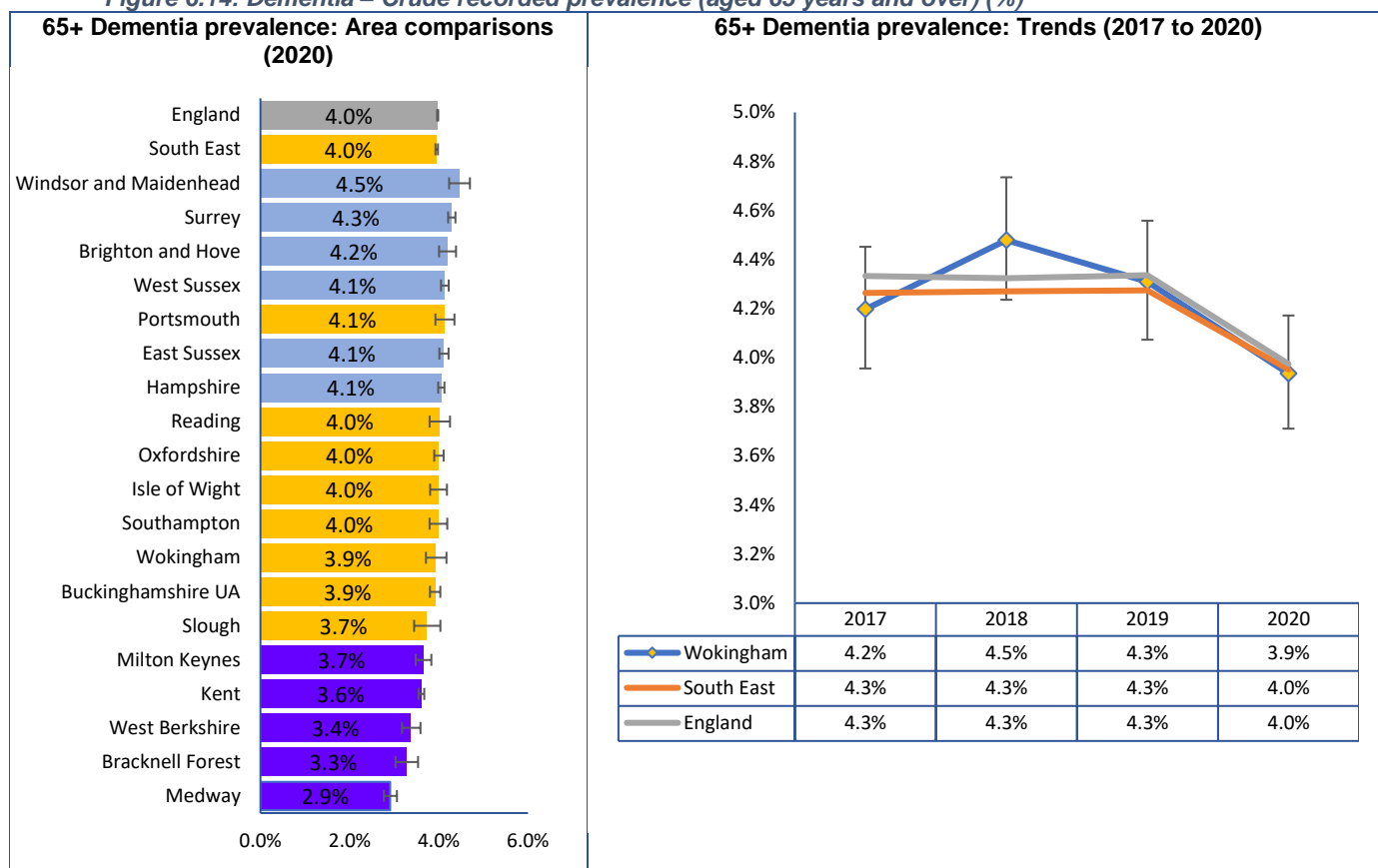


Source: NHS Digital Quality and Outcomes Framework

The recorded prevalence among those aged 65 years or older in Wokingham was 3.9% in 2020 similar to the South East and England averages of 4.0%. The local rate has remained stable over the period spanning 2017 and 2020 with a decline in 2020

most likely due to COVID-19 – similar patterns were evident at regional and national levels (Figure 6.14).

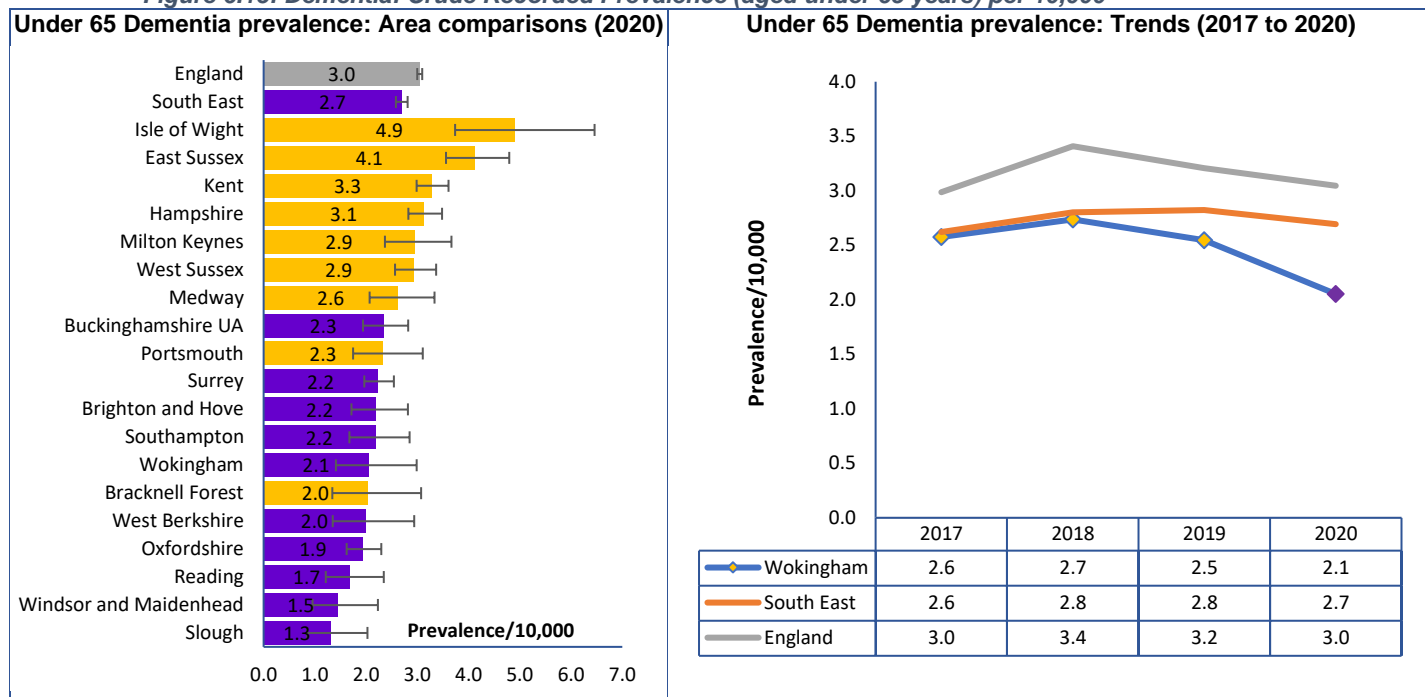
Figure 6.14: Dementia – Crude recorded prevalence (aged 65 years and over) (%)



Source: *Dementia Profile* (Office for Health Improvement and Disparities, 2022); [Recorded Dementia Diagnoses](#)

The recorded prevalence among those aged under 65 years (early-onset dementia) in Wokingham in 2020 was 2.1 per 10,000, which is significantly lower than the England average of 3.0 per 10,00 but similar to the South East average of 2.7 per 10,000. Though there has been a decline in the prevalence between 2018 and 2020, it was not statistically significant and the fall in 2020 was most likely due to the impact of COVID-19. Similar patterns were evident at regional and national levels (Figure 6.15).

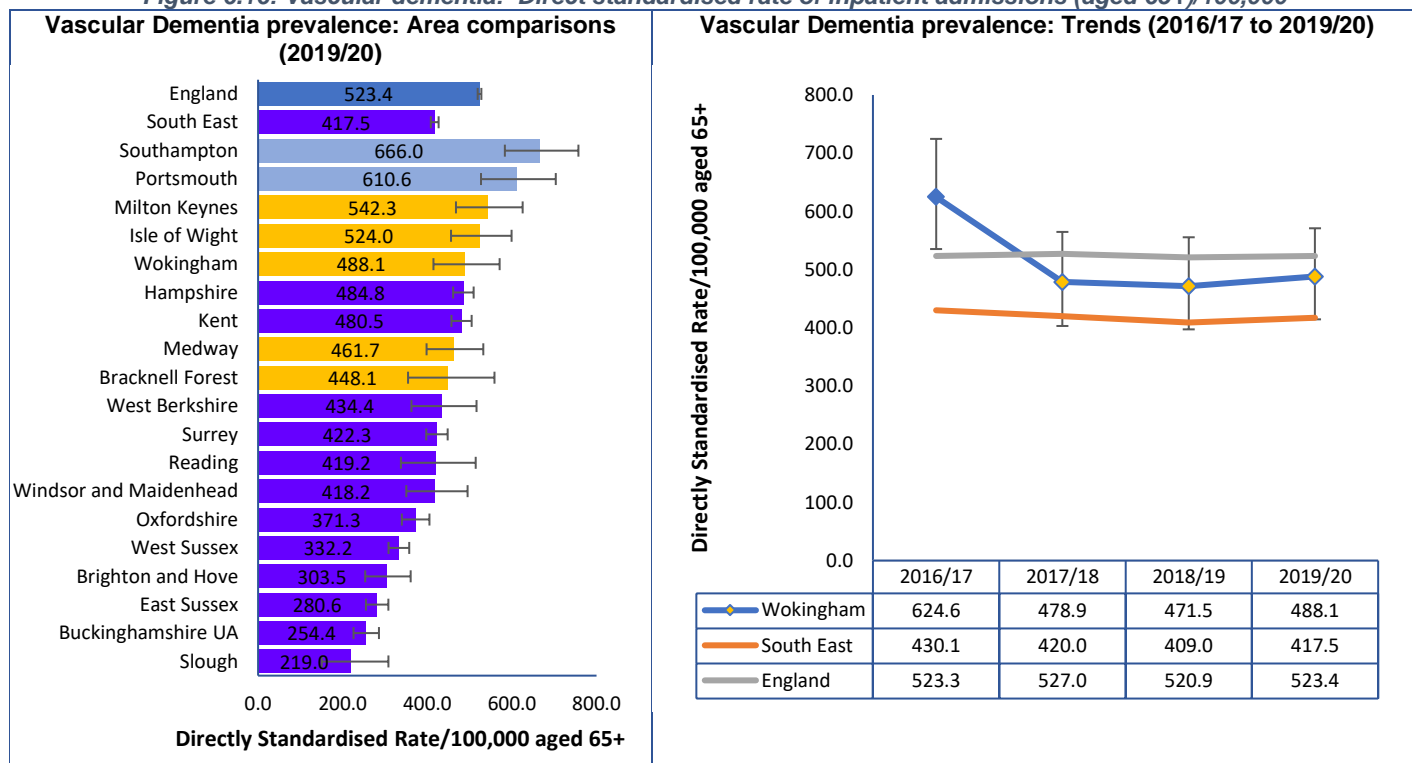
Figure 6.15: Dementia: Crude Recorded Prevalence (aged under 65 years) per 10,000



Source: *Dementia Profile* (Office for Health Improvement and Disparities, 2022)

Recorded age-standardised prevalence of vascular dementia among those aged 65 years or older in Wokingham was 488.1 per 100,000 in 2019/20, similar to the South East and England averages of 417.5 and 523.4 per 100,000 respectively (Figure 6.16). The prevalence has virtually stabilised between 2017/18 and 2019/20 after a decline from 624.6 per 100,000 in 2016/17 to 467.9 per 100,000 in 2017/18.

Figure 6.16: Vascular dementia: Direct standardised rate of inpatient admissions (aged 65+)/100,000

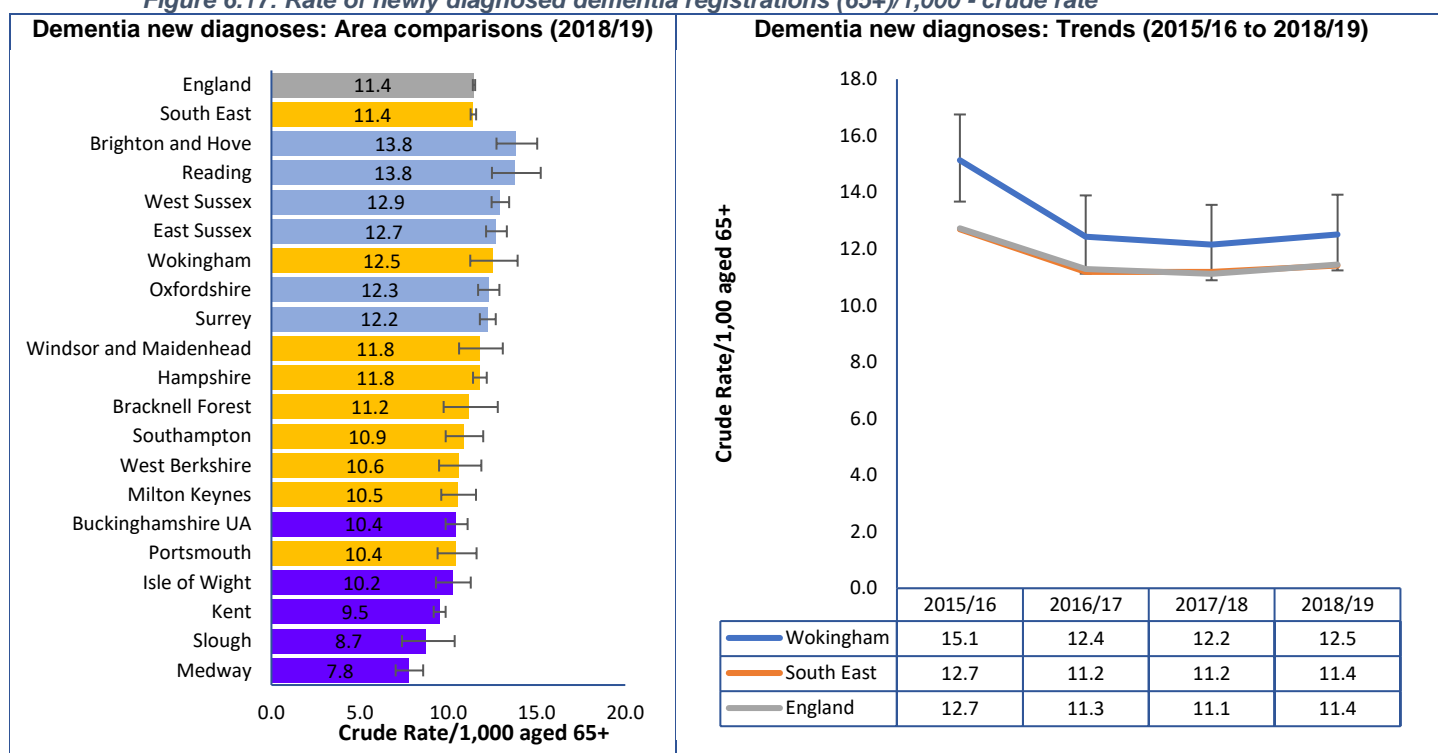


Source: *Dementia Profile* (Office for Health Improvement and Disparities, 2022)

The rate of newly diagnosed dementia registrations provides an insight into the number of patients who are newly diagnosed with dementia and registered with a GP. Used alongside the prevalence figure, it can provide an indication of the growth in burden of dementia and the dementia-related needs within local areas.

On average 330 new cases of dementia are diagnosed in those aged 65 years or older in Wokingham each year. In 2018/19, the crude new diagnosis rate among those aged 65 years or older in Wokingham was 12.5 per 1,000 in 2018/19, similar to the South East and England averages of 11.4%. Though the rate has declined between 2015/16 and 2018/19, it was not statistically significant. Similar patterns were seen at both regional and national levels (Figure 6.17).

Figure 6.17: Rate of newly diagnosed dementia registrations (65+)/1,000 - crude rate



Source: *Dementia Profile* (Office for Health Improvement and Disparities, 2022)

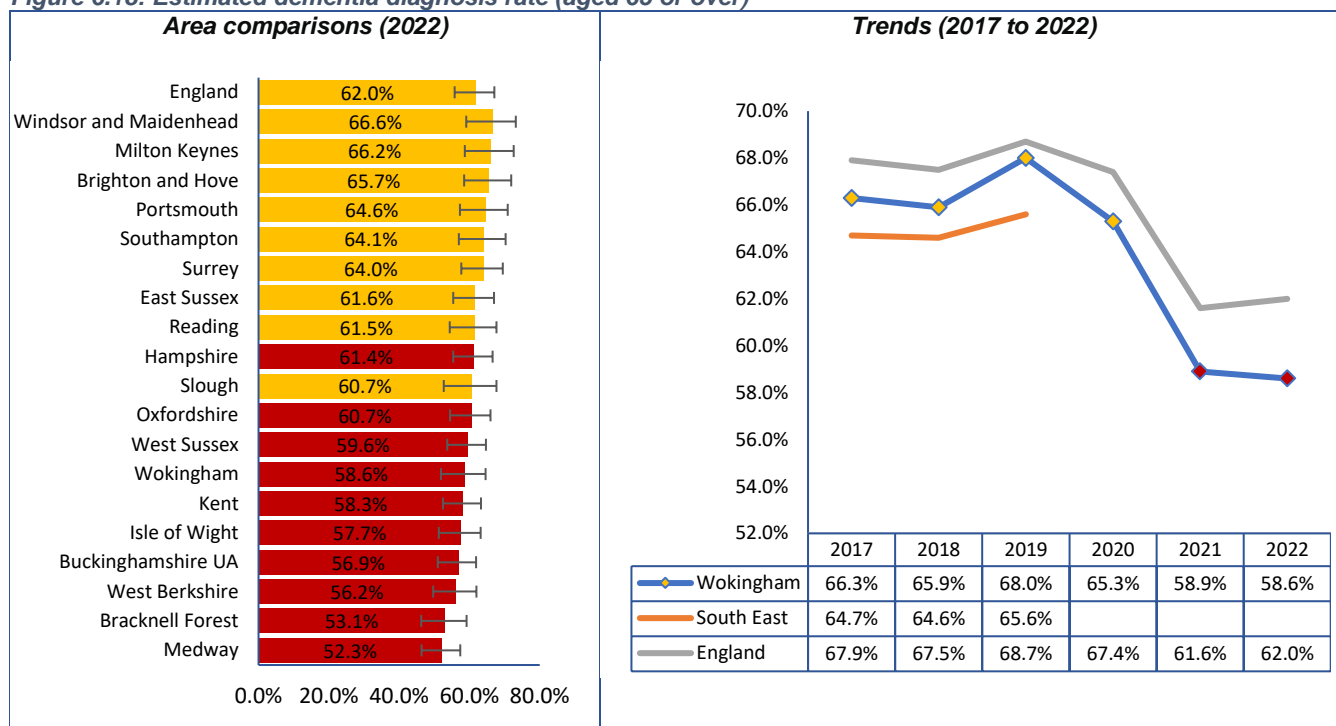
6.5.1 Dementia diagnosis rate

This is proportion of persons aged 65 or older with a recorded diagnosis of dementia compared with the number of people expected/estimated to have dementia, given the characteristics of the population and the age and sex specific prevalence rates of the [Cognitive Function and Ageing Study II](#) (Office for Health Improvement and Disparities, 2022).

There is a national commitment to increase the number of people living with dementia who have a formal diagnosis. This commitment was further supported by the NHS 2014-15 mandate which set a target for increasing the estimated dementia diagnosis rate. The rationale for this is that a timely diagnosis enables people living with dementia, their carers and healthcare staff to plan accordingly and work together to improve health and care outcomes (Office for Health Improvement and Disparities, 2022).

In Wokingham only 58.9% of the expected dementia cases were diagnosed and registered with their GPs in 2022, significantly lower than the threshold of **66.7%** for this indicator for comparison - the England averages was 62.0% (which was not significantly lower than the 66.7% threshold) but there was no data for the South East. The diagnosis rate declined significantly from the peak of 68.0% in 2019 at which point it was similar to the national average of 68.7% to the lowest recorded figure of 58.6% in 2022 becoming statistically significantly lower than the national average (Figure 6.18). The impact of COVID-19 is evident in the trends for Wokingham and national levels.

Figure 6.18: Estimated dementia diagnosis rate (aged 65 or over)



Source: *Dementia Profile* (Office for Health Improvement and Disparities, 2022)

6.6 Mental health comorbidity in people with dementia

Dementia and mental health problems are not mutually exclusive, and there is a subset of the population living with both. Though some of these mental health conditions are recognised risk factors for developing dementia, they can also become consequences of dementia.

6.6.1 Dementia and Depression

Depression affects 20% to 32% of persons with dementia: the prevalence is higher in patients with vascular dementia than in patients with Alzheimer disease (Shub & Kunik, 2009). Depression is often diagnosed when a person is in the early stages of dementia, but it can develop at any stage and can be episodic (Alzheimer's Society, 2022).

6.6.2 Dementia and Anxiety

Community prevalence of Generalized anxiety disorder (GAD) in patients with dementia is nearly 20%.6 and occurs in 5% of patients with Alzheimer's Disease. Estimates of clinically significant anxiety are as high as 70%, depending on the

clinical sample (higher for vascular and frontotemporal dementias) and screening modality (lower in studies that employed structured clinical interviews) (Shub & Kunik, 2009).

Anxiety may be higher in vascular dementia than in Alzheimer's disease, and it decreases in the severe stage of dementia. It is also associated with poor quality of life, behavioural disturbances, and limitations in activities of daily living (Seignourel, Kunik, Snow, Wilson, & Stanley, 2008).

6.6.3 Dementia and Psychosis

Psychosis can develop in people living with dementia as a feature of the progression of the disorder and can be expressed as, delusions, aggression, hallucinations, apathy, and sleep disturbance.

Psychotic symptoms of delusions and hallucinations have been shown to be present in 18% and 14%, respectively, of patients with dementia in a community-based cohort. Considerably higher estimates are often quoted in clinical samples, especially in patients with Lewy body dementia (Shub & Kunik, 2009), e.g., prevalence of psychotic symptoms in patients with Alzheimer's disease has been estimated by some to be 41.1% (Ropacki & Jeste, 2005).

6.6.4 Learning Disabilities and dementia

Studies have estimated that 1 in 50 people with Down's syndrome develop dementia in their 30s, rising sharply to more than half of those who live to 60 or over. By comparison, the number of people among the population without learning disability aged 60-69 years who develop dementia is about 1 in 75 (Alzheimer's Society, 2022). Among those with other learning disabilities other than Down's syndrome, studies suggest that approximately 1 in 10 people aged 50 to 65 have dementia and this rises to more than half of those aged 85 or over (Alzheimer's Society, 2022).

6.7 Provision and care of people with dementia

6.7.1 Management and Treatment of Dementia

There is currently no cure for dementia and no one-size-fits-all interventions are available. However, individuals can live well with dementia with the help of various interventions including, medications, support services and psychosocial interventions tailored to their needs.

Medications are mainly used to reduce symptoms and progression of the condition and, in those with moderate to severe dementia, and to treat behavioural and psychological symptoms. Psychosocial interventions are aimed at helping people to live well following diagnosis.

Psychosocial interventions can help with (Guss, et al., 2014):

- Coming to terms with a diagnosis of dementia
- Maintaining social life and relationships after diagnosis
- Reducing stress and improving mood
- Thinking and memory (cognitive function)
- Living independently

- Quality of life – maintaining health and happiness

Other interventions include:

- Maintenance Cognitive Stimulation Therapy (MCST): This involves group activities and exercises designed to improve memory, language ability and problem-solving skills. This can benefit people with mild to moderate Dementia.
- Cognitive rehabilitation: This involves working with trained professionals, e.g., occupational therapist, relative or friend to achieve a personal goal, such as learning to use a mobile phone or other everyday tasks. This can help individuals in the initial stages of dementia cope better with the condition.
- Reminiscence and life stories involving talking about events from individual's past.

Studies have shown the co-occurrence of dementia and mental health problems in later life, indicating that a higher proportion of people living with dementia will also be experiencing physical and mental health problems than those without dementia (Regan, 2016). Therefore, it is important that management methods consider the likelihood of co-occurring mental health problems in their design and delivery.

6.7.2 Living well

6.7.2.1 Care plan review

Existing evidence shows that patients with Alzheimer-type dementia do not complain of common physical symptoms but experience them to the same degree as the general population. As a result, it has been recommended that patient assessments, which inform their care plans, should include the assessment of any behavioural changes caused by the following (Office for Health Improvement and Disparities, 2022):

- Concurrent physical conditions (e.g., joint pain or intercurrent infections)
- New appearance of features intrinsic to the disorder (e.g., wandering) and delusions or hallucinations due to the dementia or as a result of caring behaviour (e.g., being dressed by a carer)
- Depression which is more common in patients living with dementia than those without.

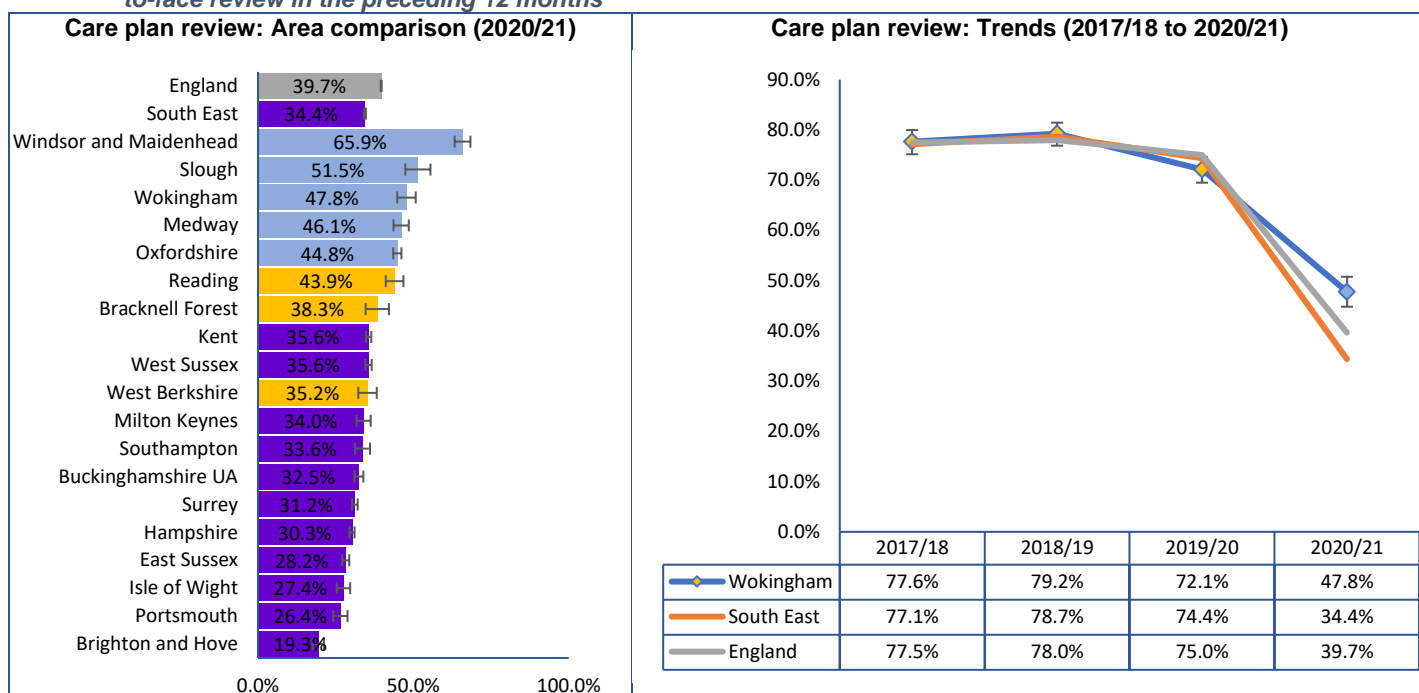
The care plan reviews should focus on support needs of the patient and their carer. The review should address four key areas outlined below (Office for Health Improvement and Disparities, 2022):

- Physical and mental health review for the patient
- The carer's requirement for patient information that meet the stage of illness and carers or patient's health and social care needs (if applicable)
- How the care of the individual will impact the caregiver (if applicable)
- Co-ordination arrangements and communication with secondary care (if applicable)

The indicator relating to care plan review is intended to assess how well local plans are being informed by the needs of those with dementia whose needs can change

rapidly. The percentage of patients diagnosed with dementia whose care plan has been reviewed in a face-to-face review in the preceding 12 months was 47.8% in Wokingham in 2020/21. Though this was significantly above both the South East and England averages of 34.4% and 39.7% respectively (Figure 6.1), it represented less than half of dementia patients whose care plans should have been reviewed within the period under review. There has been a significant decline in this indicator between 2019/20 and 2020/21, which was most likely due to the impact of COVID-19 – similar patterns were evident at both regional and national levels (Figure 6.19).

Figure 6.19: Percentage of patients diagnosed with dementia whose care plan has been reviewed in a face-to-face review in the preceding 12 months



Source: *Dementia Profile* (Office for Health Improvement and Disparities, 2022)

6.7.2.2 Isolation among dementia carers

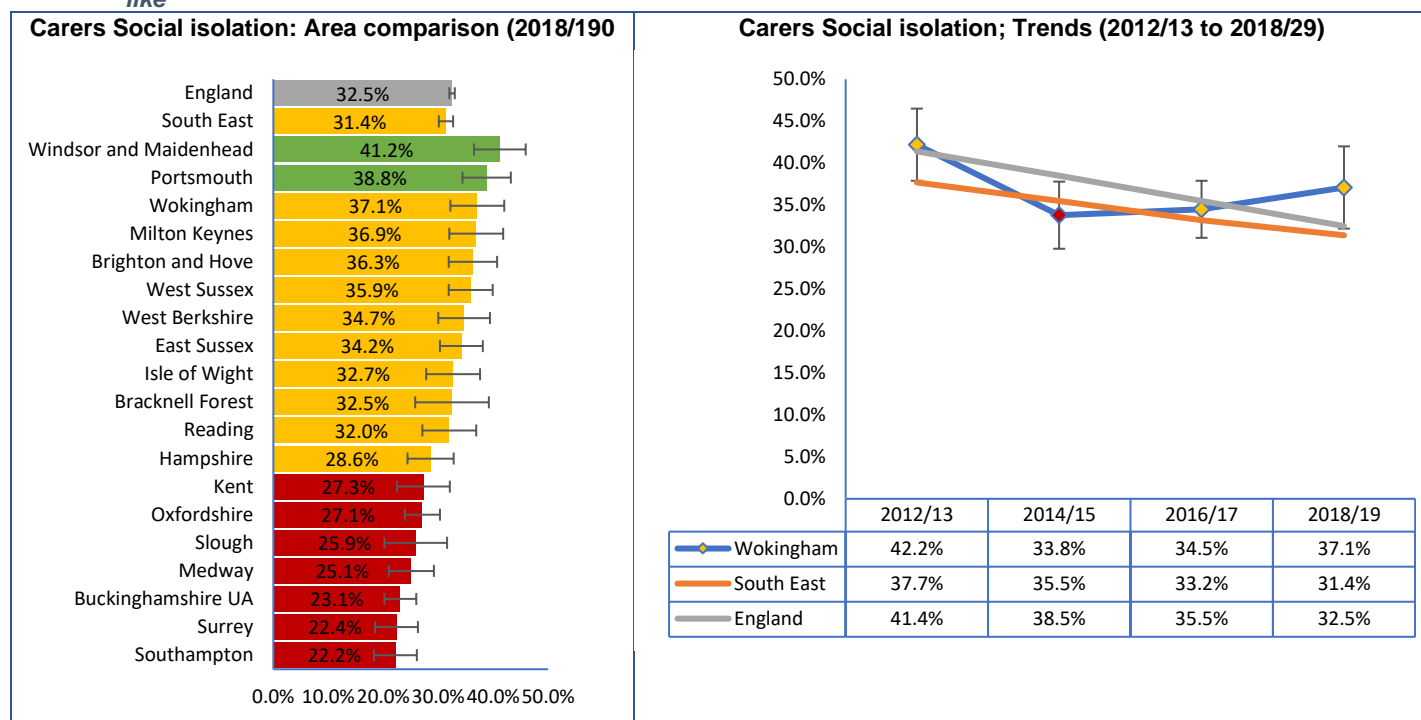
There is a link between loneliness and poor mental and physical health. A British study (Victor, et al., 2021) found 43.7% of caregivers reported moderate loneliness and 17.7% reported severe loneliness. Greater social isolation and increased caregiving stress has been linked with both moderate and severe loneliness. Better quality of relationship with the person with dementia along with increased levels of well-being and life satisfaction have also been linked with a lower relative risk of reporting both moderate and severe loneliness. Interventions aimed at reducing caregiving stress and supporting meaningful relationships may go some way to reduce loneliness (Victor, et al., 2021).

The proportion of carers² who reported they had “as much social contact as they would like” in Wokingham was 37.1% in 2018/19, comparable to the South East and England averages of 31.4% and 32.5% respectively (Figure 6.20). Though there has been an increase in this indicator between 2014/15 and 2018/19 from 33.8% to

² Those people in receipt of long-term support services funded or managed by social services following a full assessment of need

37.1%, this was not statistically significant. However regional and national trends were downward overall (Figure 6.20).

Figure 6.20: Social Isolation: percentage of adult carers who have as much social contact as they would like



Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

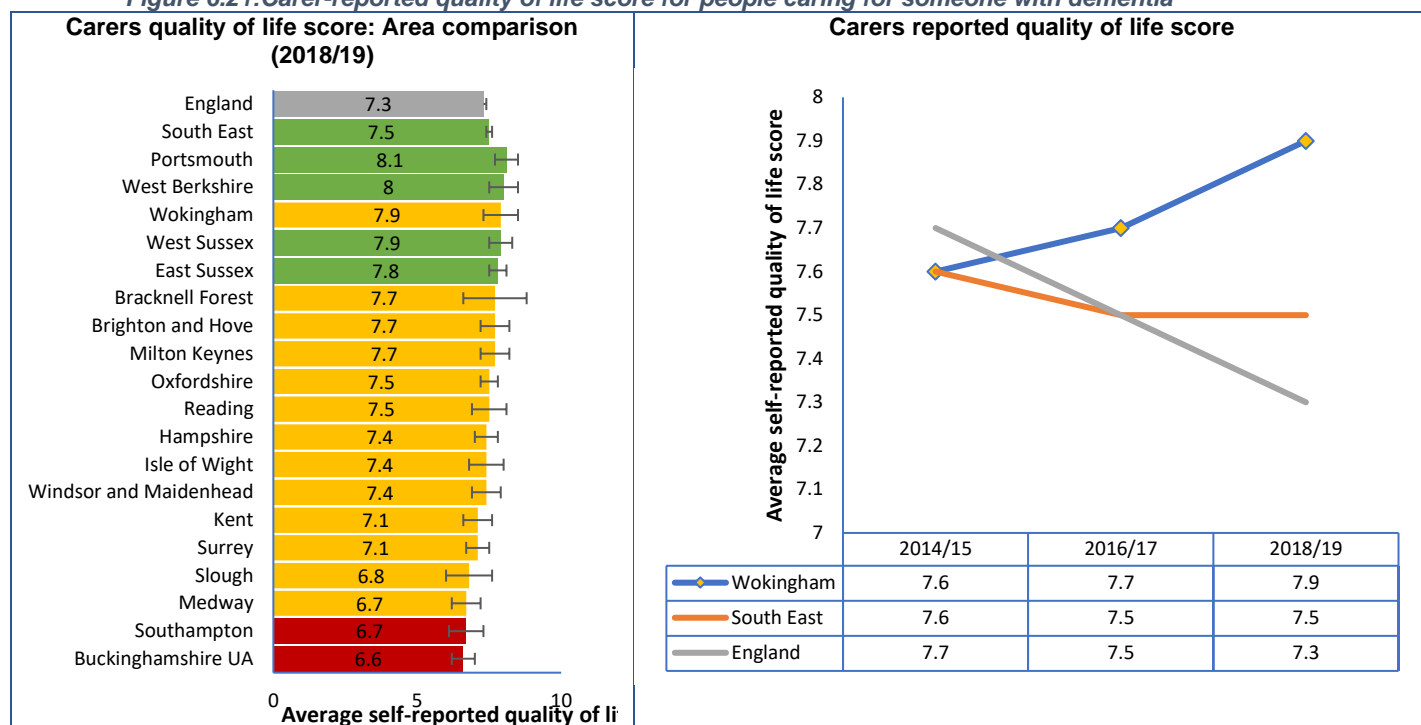
6.7.2.3 Carers' quality of life

A German study found that caring for a relative with dementia is associated with poorer health, i.e., greater levels of subjective burden and depressiveness, and predicts lower care-related quality of life in caregivers, emphasizing the importance of specific interventions aiming to support dementia patients' informal caregivers (Karg, Graessel, Randzio, & Pendergrass, 2018).

The 2018/19 Personal Social Services Survey of Adult Carers in England showed that 60.6% of carers reported that caring had caused them feelings stressed, compared with 58.7% in 2016-17; 53.4% of carers reported that their caring caused them no financial difficulties, while 10.6% of carers stated caring caused them a lot of financial difficulties, which was a significant increase from the 2016-17 figure of 9.6% (NHS Digital, 2019).

The average carer-reported quality of life score was 7.9 out of a possible 12 among Wokingham dementia carers in 2018/19 which was not statistically significantly different from the South East and England averages of 7.5 and 7.3 respectively. Though there was an upward trend in the reported scores between 2014/15 and 2018/19, the increase was not statistically significant. However, regional and national scores followed a downward trend over the same period (Figure 6.21).

Figure 6.21: Carer-reported quality of life score for people caring for someone with dementia



Source: *Dementia Profile* (Office for Health Improvement and Disparities, 2022)

6.7.3 Supporting well

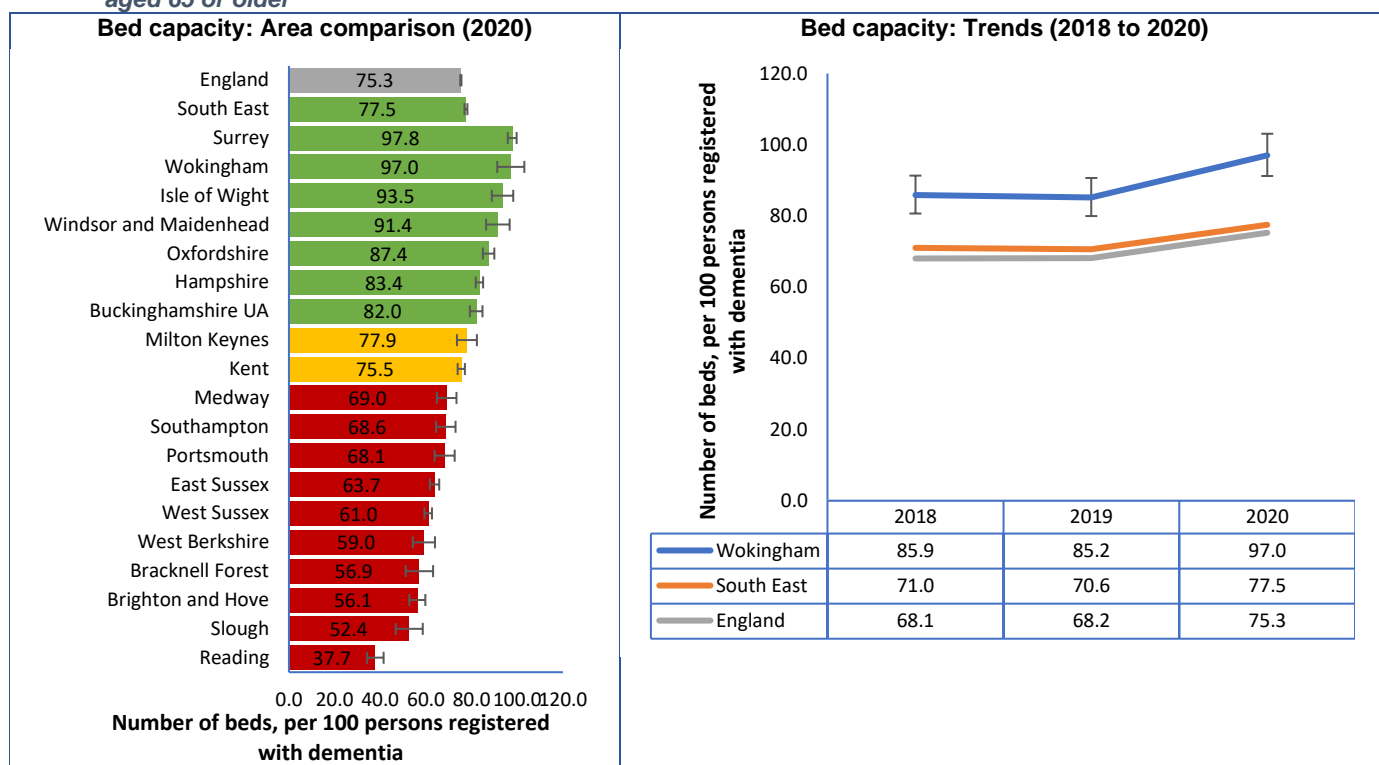
6.7.3.1 Access to high-quality care home beds

The Prime Minister’s ‘[Challenge on Dementia 2020](#)’ (Department of Health, 2015) committed to improving access to safe and high-quality long-term care services for people living with dementia. It is estimated that 70% of those leaving with dementia may eventually require long-term residential care (Office for Health Improvement and Disparities, 2022).

Adequacy of available bed capacity in care residential care and nursing homes to meet the needs of those with dementia is measured by the number of residential care and nursing home beds per 100 persons registered with dementia, aged 65 or older. The higher the capacity, the better an area is in meeting the residential and nursing needs of those with dementia.

The bed capacity in Wokingham was 97.0 per 100 registered dementia patients in 2020, significantly higher than the South East and England averages of 77.5 and 75.3 per 100 respectively. The bed capacity in Wokingham has seen a statistically significant increase from 85.9 per 100 in 2018 to 97.0 per 100 in 2020 – there were similar increases in bed capacity at both regional and national levels, but Wokingham had consistently higher bed capacity over the period (Figure 6.22).

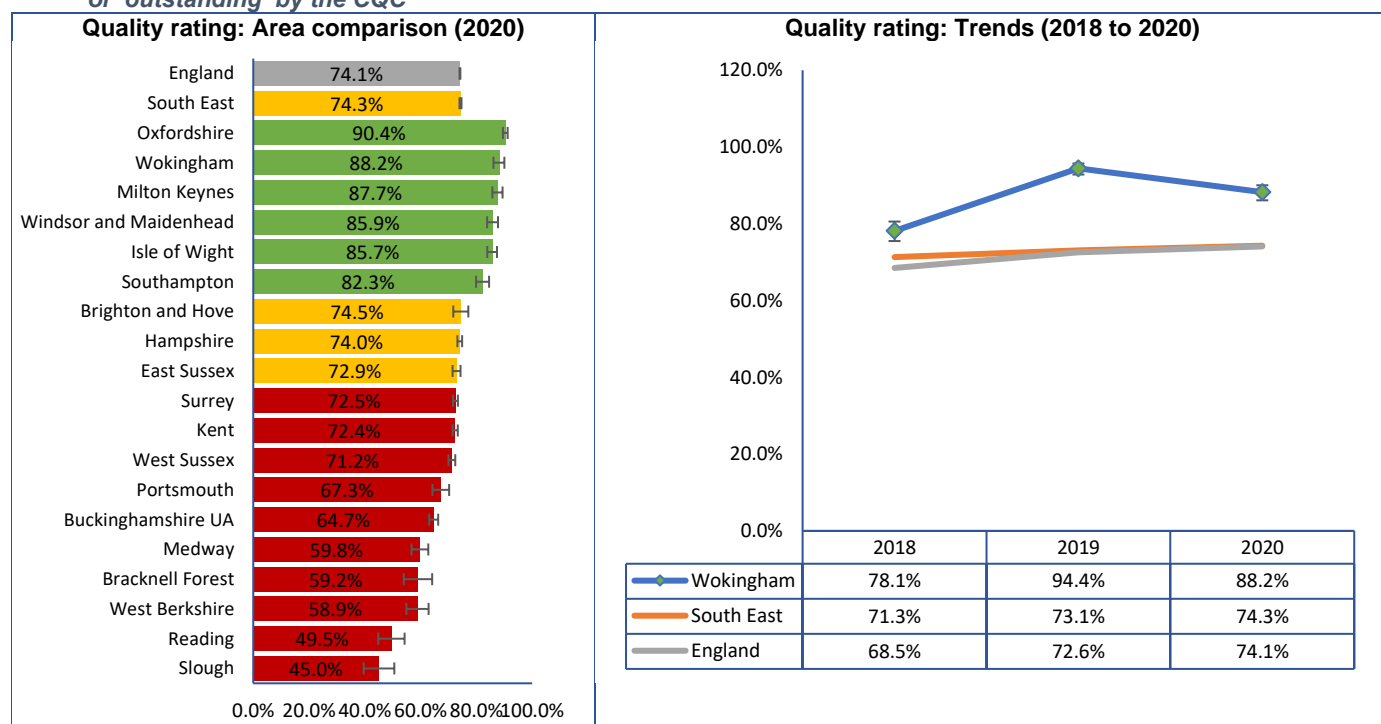
Figure 6.22: Number of residential care and nursing home beds per 100 persons registered with dementia aged 65 or older



Source: *Dementia Profile* (Office for Health Improvement and Disparities, 2022)

The proportion of residential care home and nursing home beds which have received a rating from the Care Quality Commission (CQC) reflects the ability of dementia sufferers to assess high-quality of beds suitable for managing the conditions in residential and nursing homes (Office for Health Improvement and Disparities, 2022).

Figure 6.23: Proportion of beds suitable for a person with dementia (aged 65 years or older) rated as 'good' or 'outstanding' by the CQC

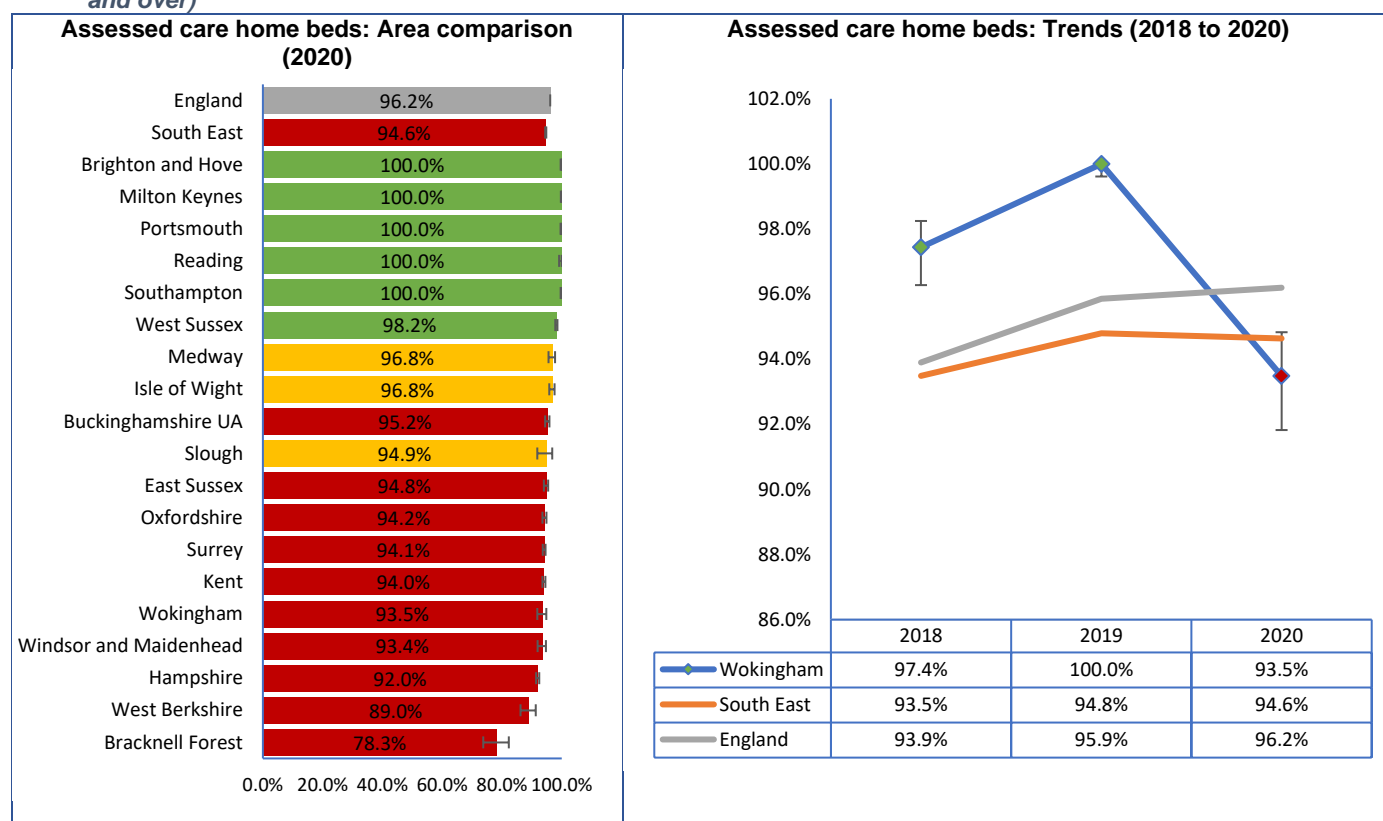


Source: *Dementia Profile* (Office for Health Improvement and Disparities, 2022)

The proportion of beds suitable for a person with dementia (aged 65 years or older) rated as 'good' or 'outstanding' by the CQC was 88.2% in Wokingham in 2020, significantly better than the South East and England averages of 74.3% and 74.1% respectively. The rate has improved significantly from 78.1% in 2018 to 94.4% in 2019 but declined slightly to 88.2% in 2020. Regional and national rates showed consistent year-on-year improvements (Figure 6.23).

In 2020, the CQC assessed 93.5% of Wokingham care and nursing homes, which was significantly less than England average of 96.2% but similar to the South East average of 94.6%. The proportion assessed in Wokingham during 2018 (97.4%) and 2019 (100.0%) were significantly higher than the respective figures at both regional and national levels (Figure 6.24). The significant drop in Wokingham was most likely due to the negative impact of the COVID-19 pandemic and meant the quality of beds in 6.5% of residential and nursing care homes were not reflected in Figure 6.23 above.

Figure 6.24: Dementia: Percentage of assessed residential care and nursing home beds (aged 65 years and over)



Source: *Dementia Profile* (Office for Health Improvement and Disparities, 2022)

6.7.3.2 Use of inpatient services

It is estimated that approximately 25% of beds in hospitals are occupied by people living with dementia. Their length of stay is often longer than that for people without dementia and there can also be delays in supporting them to leave hospital (Alzheimer's Research UK Dementia Statistics Hub, 2018).

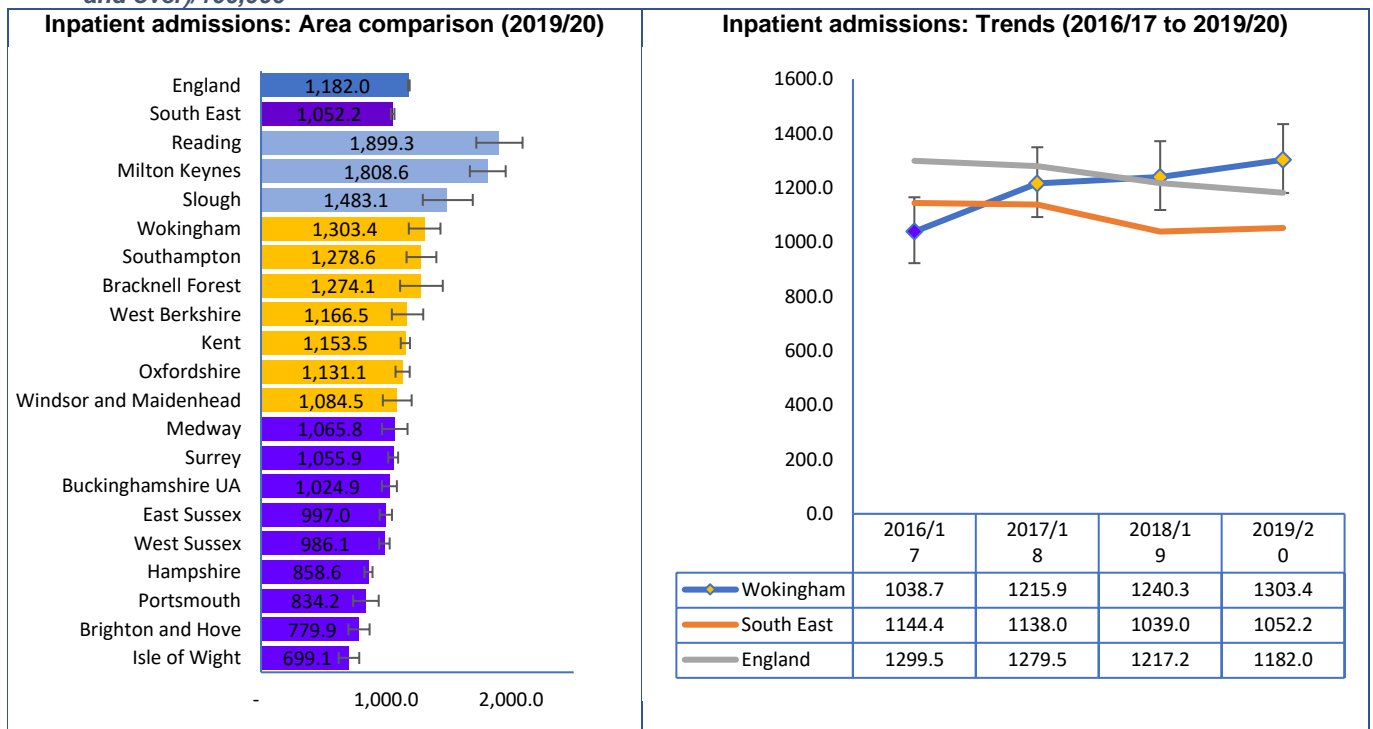
- 20% of hospital admissions in people living with dementia are for preventable conditions

- 42% of unplanned admissions to an acute hospital are for people aged over 70 years have dementia.
- The readmission rate for people living with dementia is far higher than for people without; 8.2% compared to 3.5% for elective care and 25% compared to 17% for non-elective care.

Hospital admission can trigger distress, confusion and delirium for someone with dementia, and can contribute to a decline in functioning and a reduced ability to return home to independent living (National Institute for Health and Care Excellence, 2022).

Emergency admissions constitute most of admissions among individuals living with dementia. A study in Birmingham found that between 2002 and 2007 emergency admissions constituted 95.8% of all admissions among Alzheimer disease patients, 95.4% for admission in those with vascular dementia and 96.7% of admission in those with unspecified dementia, compared with 54.4% all other groups without dementia. The proportion of patients admitted for dementia as their primary diagnosis was 5.9% among Alzheimer disease patients, 10.6% among vascular dementia patients and 6.0% among those with unspecified dementia, suggesting that earlier detection (and management) of the specific conditions may reduce emergency hospital admissions amongst dementia patients (Natalwala, Potluri, Uppal, & Heun, 2008).

Figure 6.25: Unspecified dementia: Direct age standardised rate of inpatient admissions (aged 65 years and over)/100,000

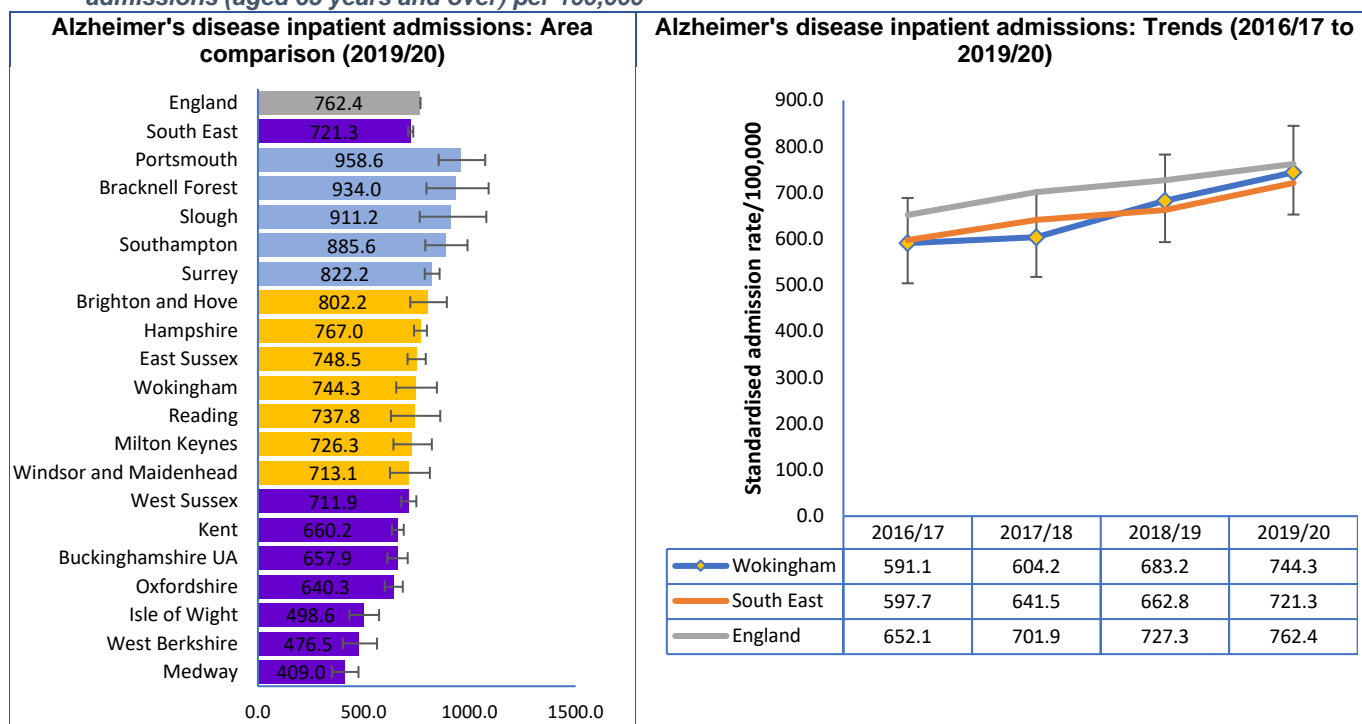


Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

The age-standardised admission rate (planned and unplanned) among individuals (age 65 years or above) with any type of dementia in Wokingham was 1,303.4 per 100,000 in 2019/20, significantly higher than the South East average of 1,052.2 per

100,000 but similar to England average of 1,182.0 per 100,000. There was a statistically significant rise in admission rate between 2016/17 and 2019/20 from 1,038.7 per 100,000 to 1,303.4 while at both regional and national levels there were downward trends – Wokingham rate was below both the regional and national averages at the beginning of period but rose sharply to go above the regional and national rates at the end of the period (Figure 6.25).

Figure 6.26: Alzheimer's disease: Direct age-standardised rate of inpatient (planned and unplanned) admissions (aged 65 years and over) per 100,000

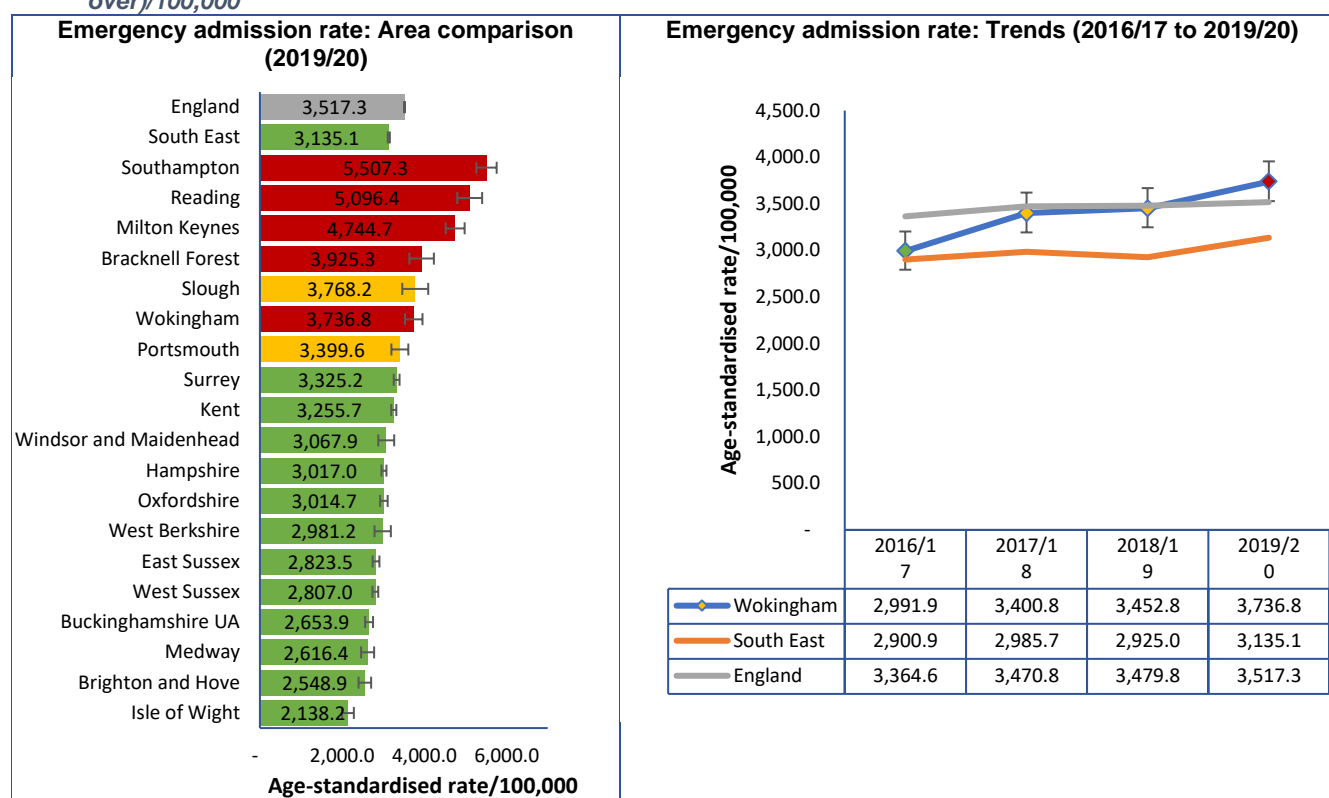


Source: **Dementia Profile** (Office for Health Improvement and Disparities, 2022)

The age-standardised hospital admission (planned and unplanned) rate among those with Alzheimer's disease in Wokingham was 744.3 per 100,000 similar to the South East and England averages of 721.3 and 762.4 per 100,000 respectively. Between 2016/17 and 2019/20 there was a faster rate of increase in admission rate compared with the trends at regional and national levels though the increase over the period was not statistically significant (Figure 6.26).

Standardised **emergency** hospital admission rate among dementia patients aged 65 years or older in Wokingham was 3,36.8 per 100,000 in 2019/20, significantly higher than the South East and England averages of 3,135.1 and 3,517.3 per 100,000. There was a statistically significant increase in the rate between 2016/17 and 2019/20 and this was at a faster rate of increase compared with regional and national trends (Figure 6.27).

Figure 6.27: Dementia: Directly age-standardised rate of emergency admissions (aged 65 years and over)/100,000

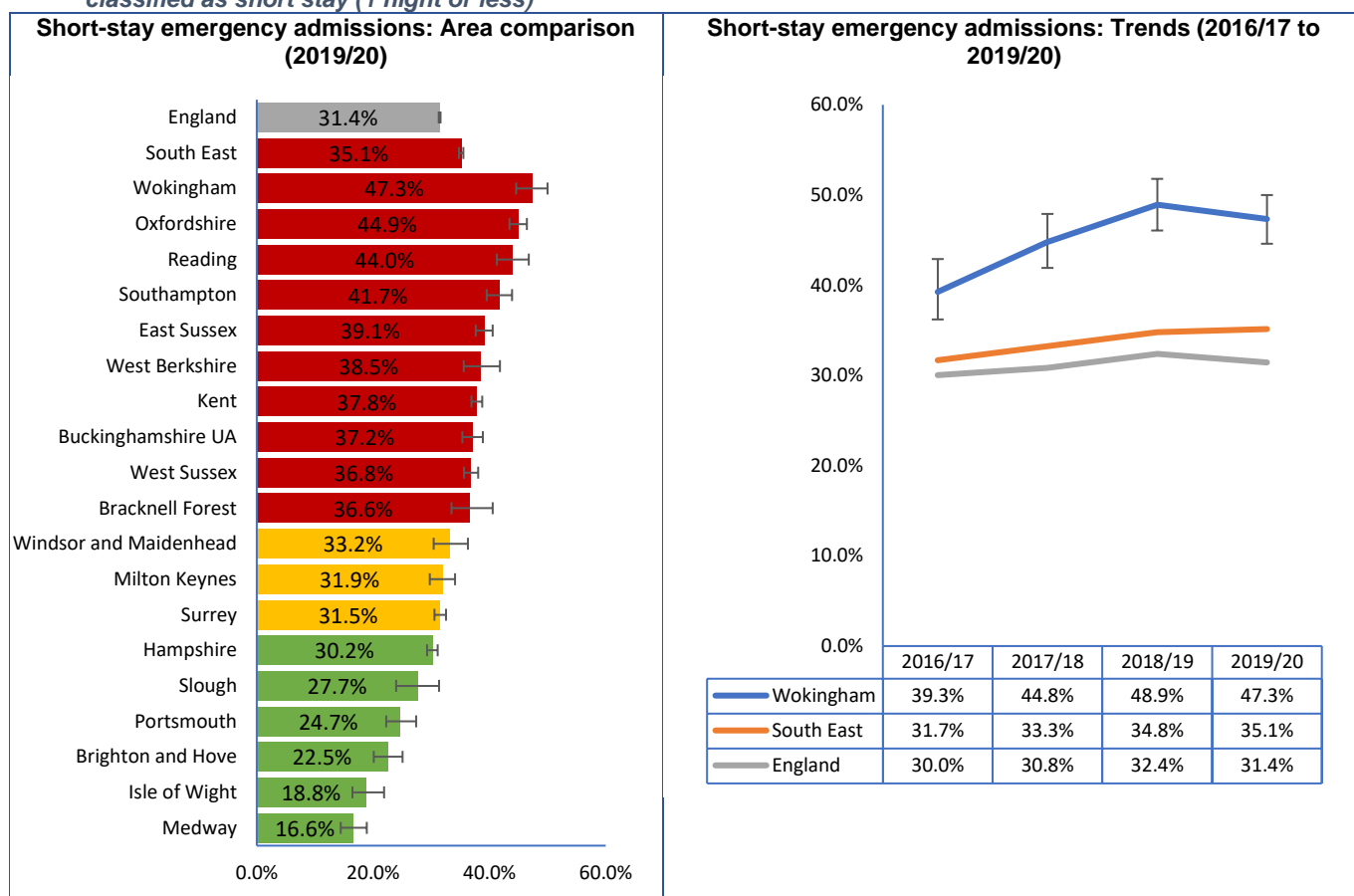


Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

Short-stay admissions are any admission episode with a duration of 1 night or less (Office for Health Improvement and Disparities, 2022). Short-stay emergency admissions as a proportion of all emergency admissions among people living with dementia aged 65 years or over was 47.3% among Wokingham residents in 2019/20, significantly higher than the respective South East and England rates of 35.1% and 31.4%. There was a statistically significant increase in the short-stay emergency rate between 2016/17 and 2019/20 from 39.3% to 47.3% in Wokingham. Though the regional and national trends were generally upward, the Wokingham rate of increase was faster (Figure 6.28).

Changes in the surrounding environment can increase the levels of anxiety and stress for an individual. People with dementia and Alzheimer’s can be more susceptible to these changes, which can cause additional distress. Admissions to hospital, particularly ones of short duration should be avoided, where possible, for this population (Office for Health Improvement and Disparities, 2022).

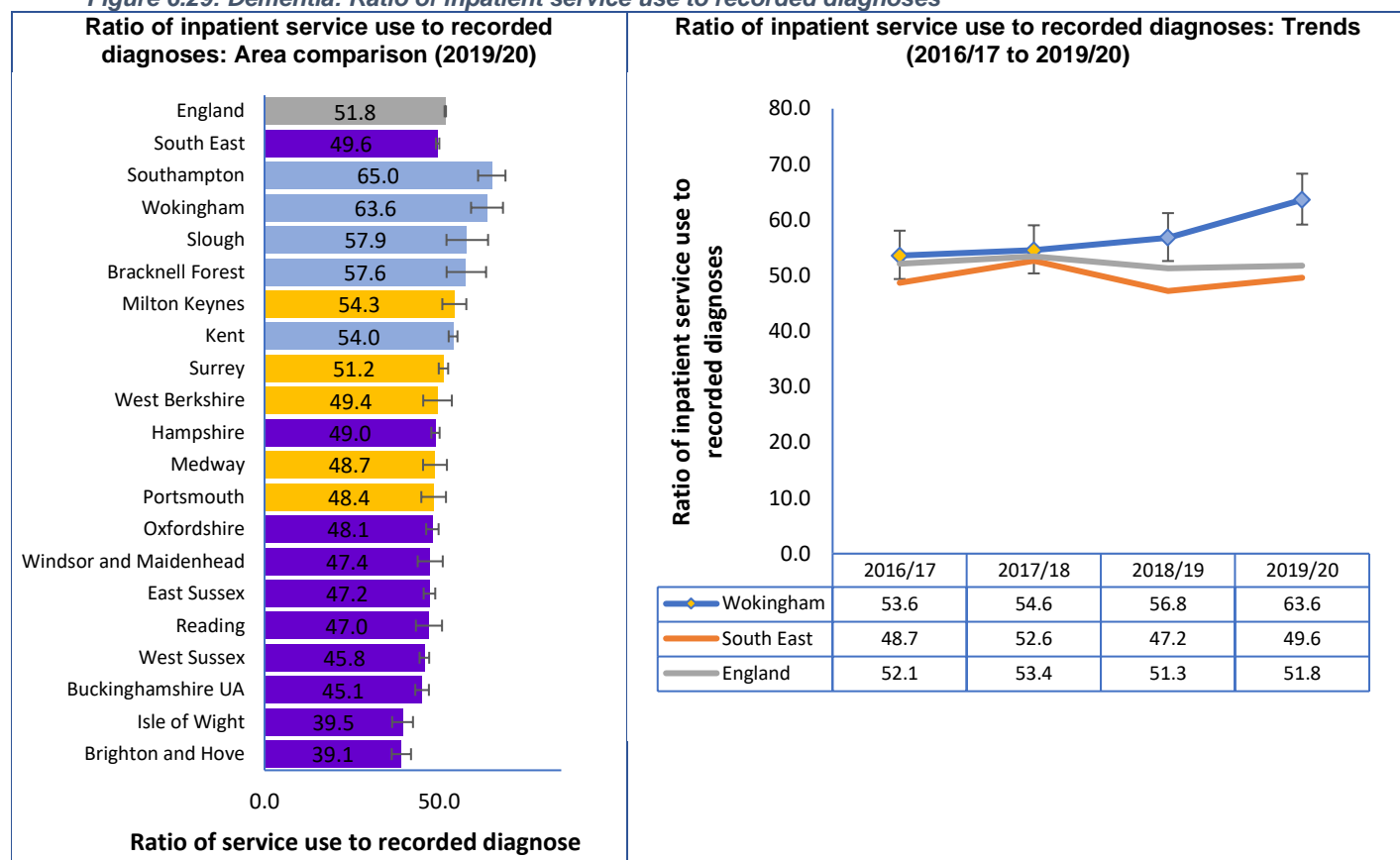
Figure 6.28: Percentage of emergency inpatient admissions for people (aged 65+) with dementia that are classified as short stay (1 night or less)



Source: *Dementia Profile* (Office for Health Improvement and Disparities, 2022)

The ratio of inpatient service use to recorded dementia diagnoses provides an indication of the use of inpatient capacity for managing dementia cases; the higher the ratio the lower the potential spare capacity to deal with any surge in inpatient care needs. The ratio was 63.6 in Wokingham in 2019/20, significantly higher than the South East and England averages of 49.6 and 51.8 respectively. In keeping with the increases seen in admission rates, the ratio has increased significantly between 2016/17 and 2019/20 from 53.6 to 63.6 while the trends at both regional and national levels have remained flat (Figure 6.29). This pattern suggests there may be significant constraints on local inpatient spare capacity in the future if the recent upward trend in the local inpatient service use continues.

Figure 6.29: Dementia: Ratio of inpatient service use to recorded diagnoses



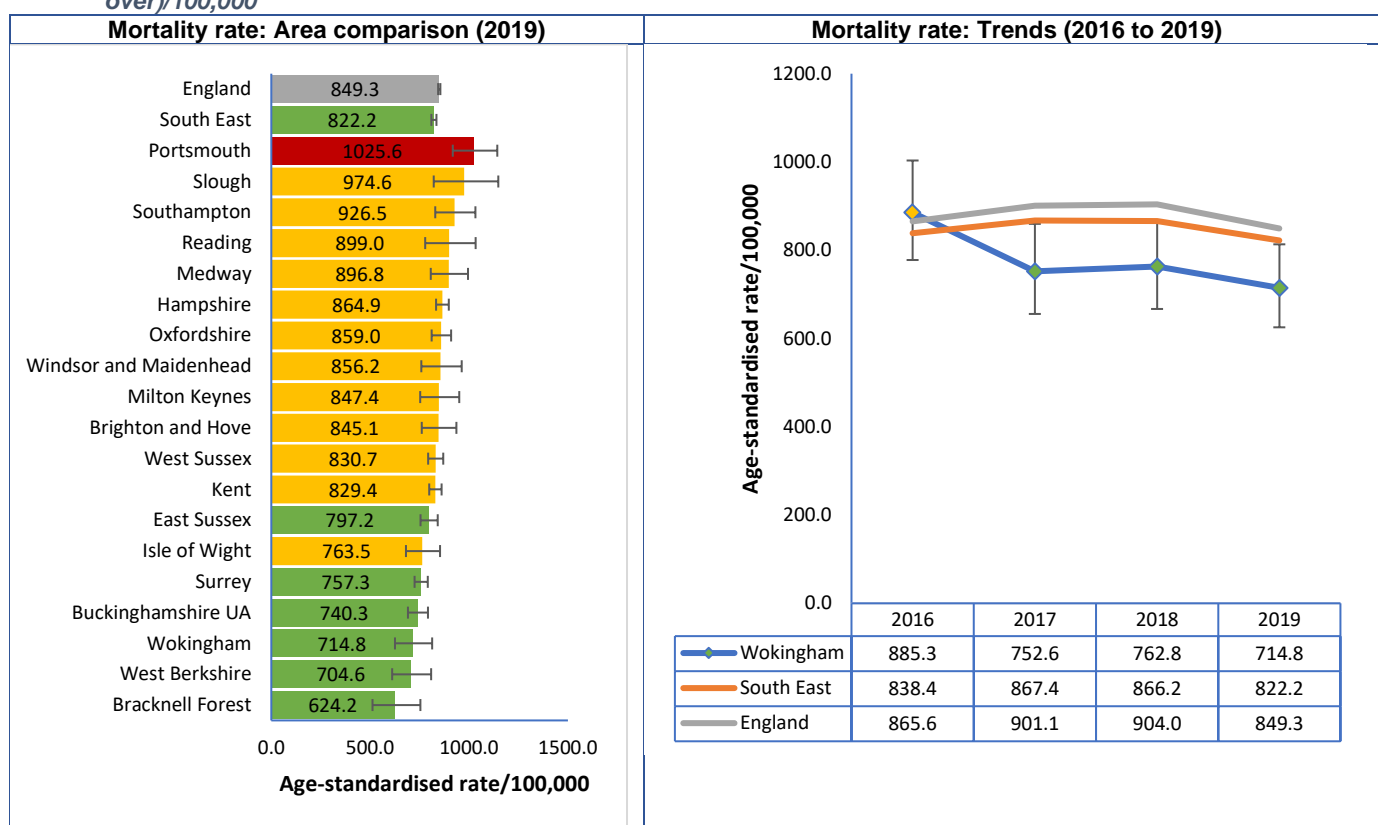
Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

6.7.4 Dying Well

6.7.4.1 Dementia death rate

Death rate among people with dementia in Wokingham is significantly lower than the South East and England averages. The age-standardised mortality rate among people with dementia aged 65 years or over in Wokingham was 714.8 per 100,000 in 2019 and was significantly lower than the South East and England averages of 822.2 and 849.3 per 100,000 respectively. Though the rate has declined in Wokingham between 2016 and 2019 from 885.3 to 714.8 per 100,000, the reduction was not statistically significant – the regional and national rates have virtually flat-lined (Figure 6.30).

Figure 6.30: Direct age-standardised mortality rate: People with dementia (aged 65 years and over)/100,000



Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

6.7.4.2 Places of death

Objective 12 of the [National Dementia Strategy](#) (Department of Health, 2009) called for improved end-of-life care for people living with dementia (Office for Health Improvement and Disparities, 2022).

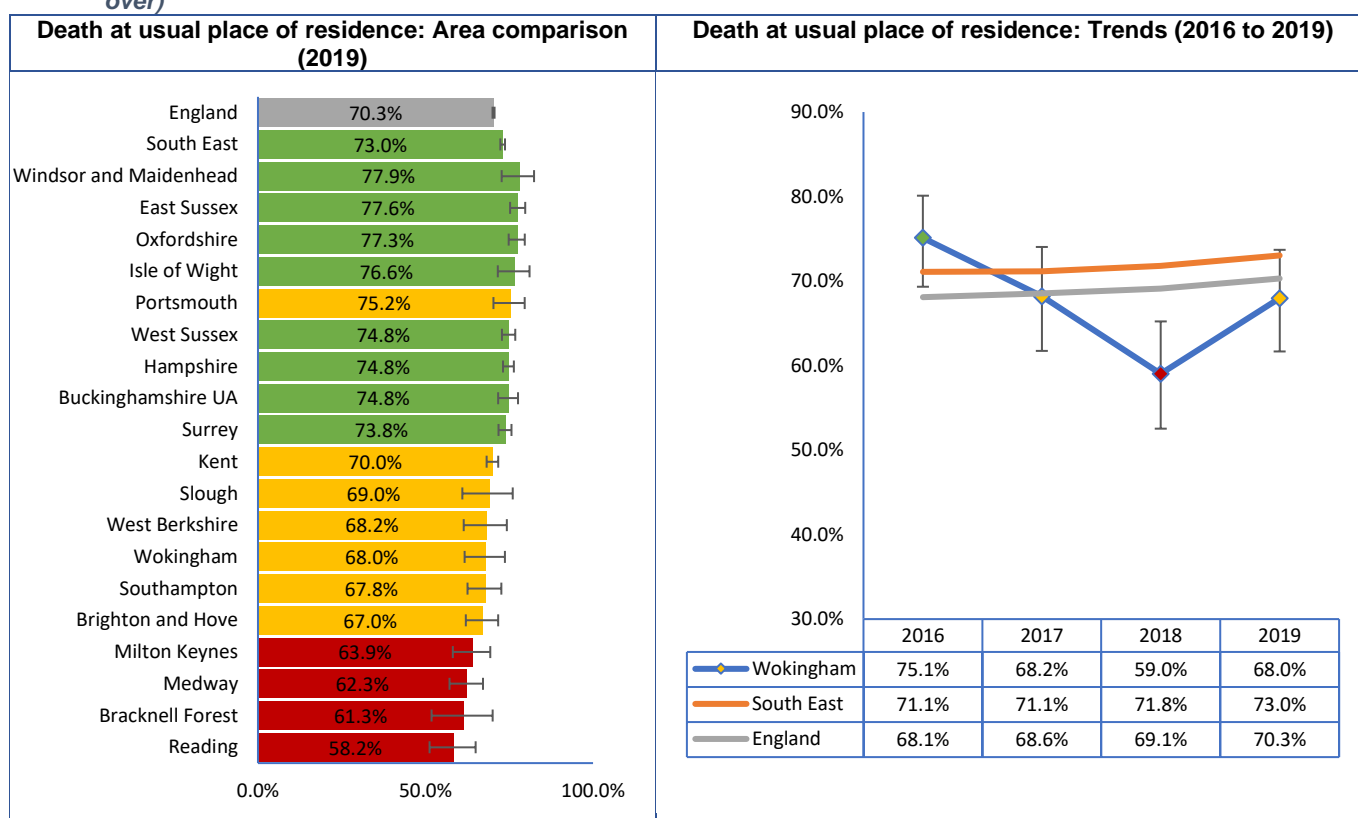
For many people, 'dying well' means the following (Alzheimer's Society, 2022):

- Being regarded with empathy and respect
- Being free from distressing symptoms and kept clean, comfortable
- Being in a recognisable place with those close to them

Trends and variations in place of death may be used as a proxy indicator for monitoring preferred place of death, a measure of the quality of end-of-life care for people with dementia or Alzheimer's aged 65 years or over (Office for Health Improvement and Disparities, 2022).

In 2019, 68.0% of deaths among those with dementia in Wokingham occurred in their usual places of residence, compared with the South East and England averages of 73.0% and 70.3% respectively though the differences were not statistically significant. The proportion declined from 75.1% in 2016 to 59.0% in 2018 but improved 68.0% in 2019 while regional and national averages showed slight improvements over the period (Figure 6.31).

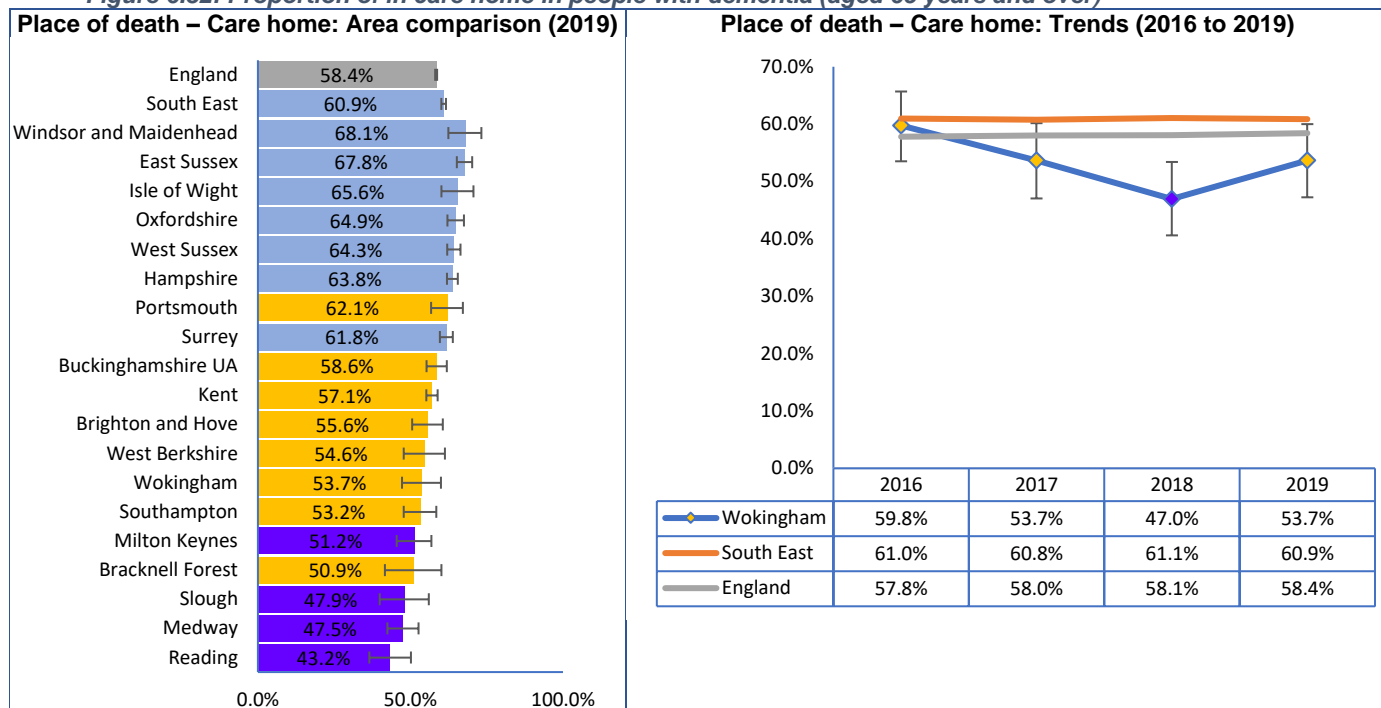
Figure 6.31: Proportion of deaths in usual place of residence in people with dementia (aged 65 years or over)



Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

The proportion dying in care homes, some of which will count as their usual places of residence, was 53.7% in Wokingham in 2019, similar to the South East and England averaged of 60.9% and 58.4% respectively. Similar to the trend seen in Figure 6.31, there was a significant decline in the proportion dying in care homes between 2016 and 2018 from 59.8% to 47.0% but increased to 53.7% in 2019 – regional and national trends remained flat (Figure 6.22).

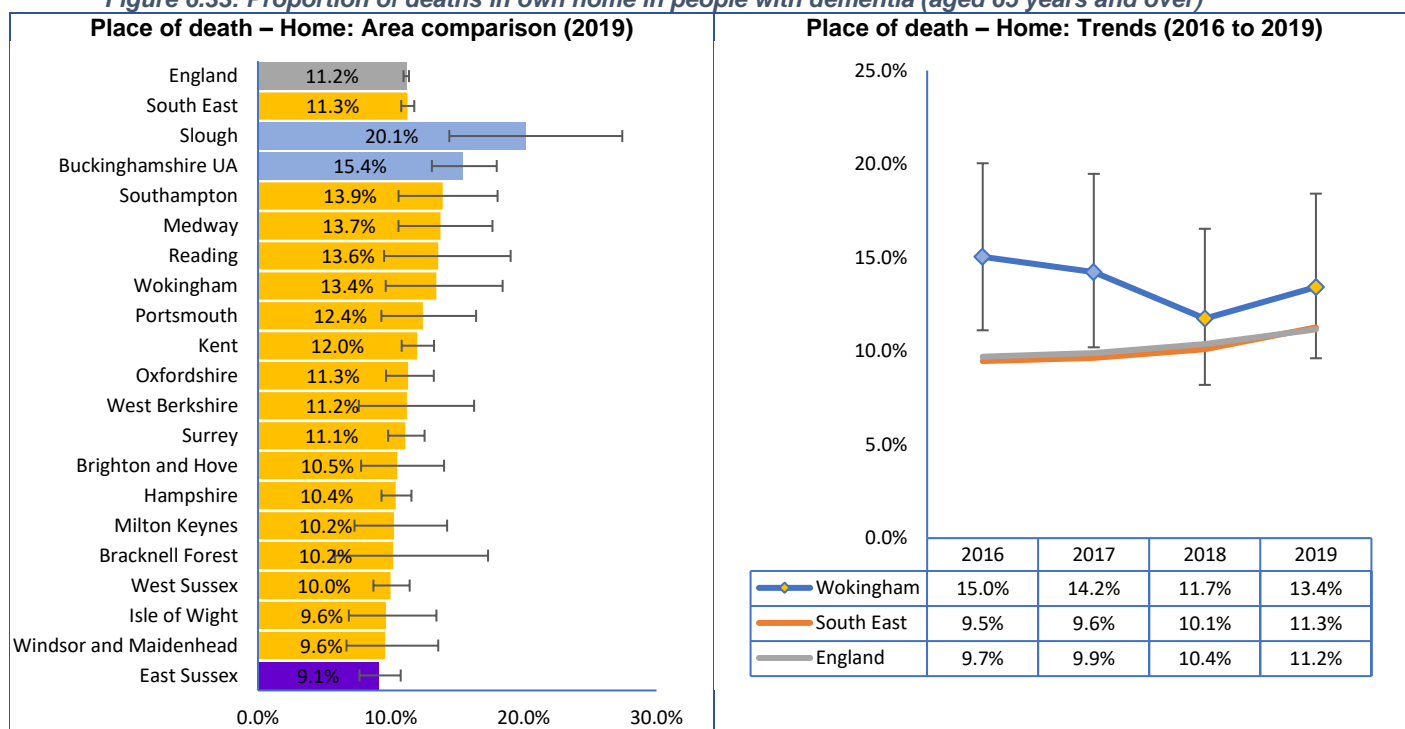
Figure 6.32: Proportion of in care home in people with dementia (aged 65 years and over)



Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

The proportion of those dying at home was 13.4% in Wokingham in 2019, which was not significantly different from the South East and England averages of 11.3% and 11.2% respectively. The trend in Wokingham was similar to those observed for deaths in usual place of residence and care homes. The overall decline in deaths occurring in homes brought the local rate in line with regional and national averages between 2018 and 2019 (Figure 6.33).

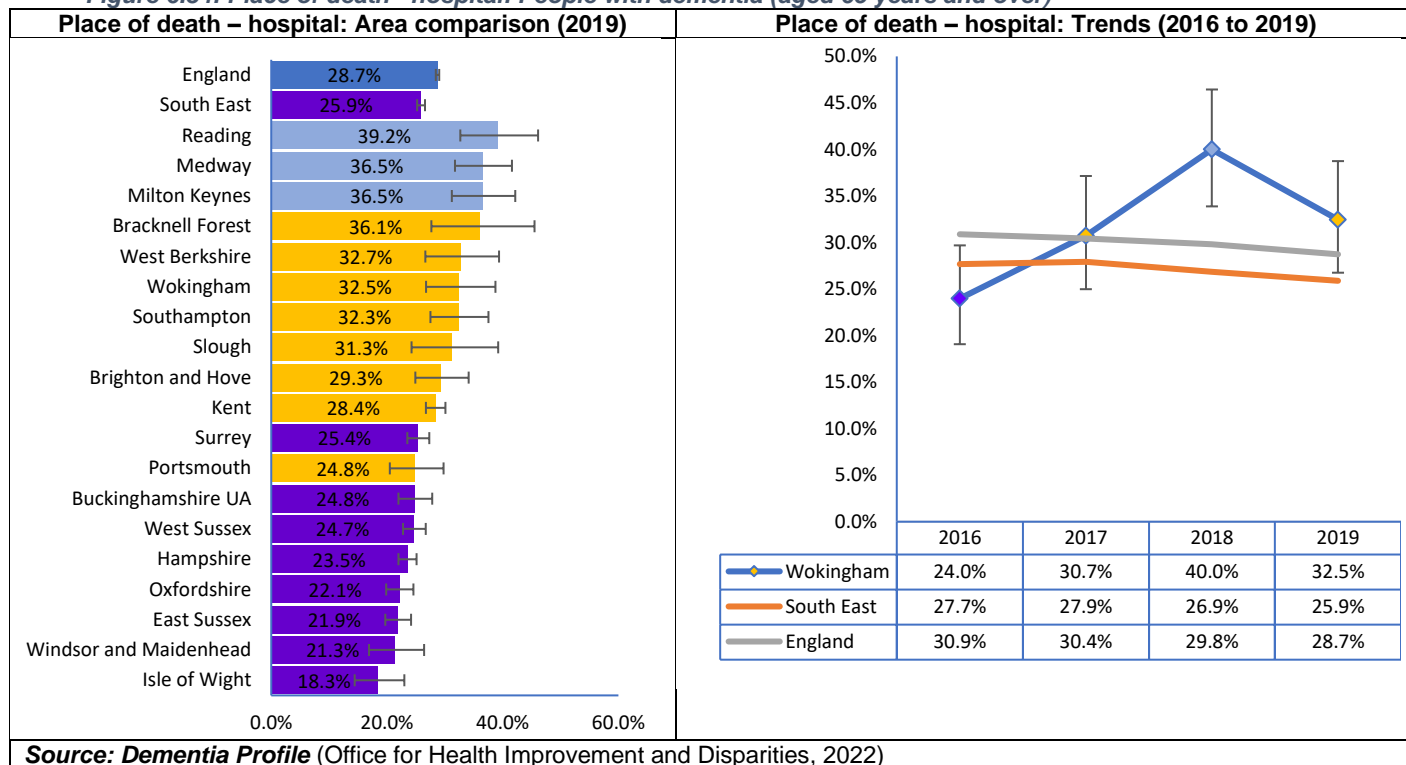
Figure 6.33: Proportion of deaths in own home in people with dementia (aged 65 years and over)



Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

The proportion dying in hospital was 32.5% in Wokingham in 2019, which was not significantly different from the England average of 28.7% but significantly higher than the South East average of 25.9% (Figure 6.34). The trend for Wokingham was the reverse of those for the proportions dying in their usual places of residence (Figure 6.31) and care homes (Figure 6.32).

Figure 6.34: Place of death - hospital: People with dementia (aged 65 years and over)

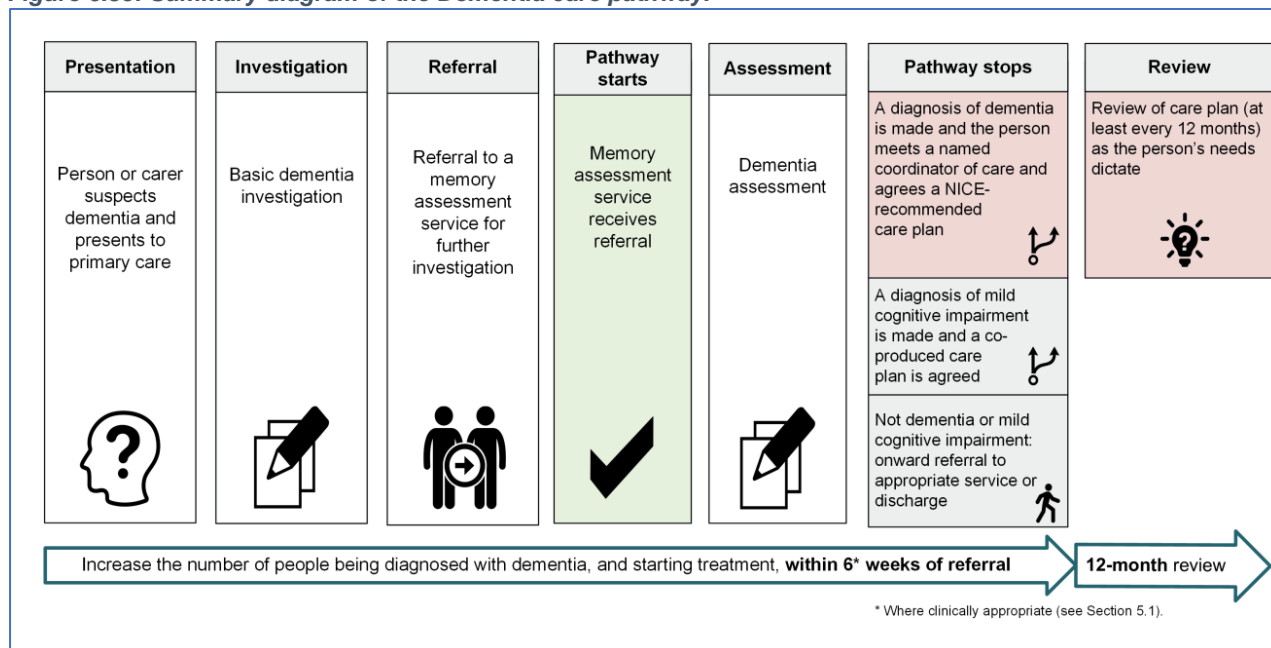


Source: Dementia Profile (Office for Health Improvement and Disparities, 2022)

6.8 The Dementia Care Pathway

Figure 6.35 provides an overview of the recommended dementia care pathway (National Collaborating Centre for Mental Health, 2018).

Figure 6.35: Summary diagram of the Dementia care pathway.



Source: (National Collaborating Centre for Mental Health, 2018)

6.8.1 Local dementia services

At the time of writing the needs assessment, Berkshire West Clinical Commissioning Group (CCG) were working on a Berkshire West Dementia Action Plan project to support the following themes within Dementia care:

1. Dementia Diagnosis Rate
2. Keeping People with Dementia Healthy
3. Creating Dementia Friendly Communities
4. Service transformation: Providing an easy to navigate journey
5. Keeping Carers healthy
6. Supporting care home residents
7. Carers Assessments

Many partners expressed the need for a local clinical pathway to be developed outlining patients journey from diagnosis to support available. The pathway would be fully developed in the plan to align with the recommended pathway in Figure 6.35.

A non- clinical pathway (The Dementia Journey) was also being developed by Age UK Berkshire at time of writing the needs assessment and would be available on the West Berkshire dementia friendly website.

6.8.2 Local services supporting prevention

The Wokingham Public Health Team and partner services support the reduction of the highlighted 12 risk factors of dementia through local public health campaigns, commissioned services, and projects. See Figure 13 Table below for local activities offered to contribute to dementia prevention.

Table 6.1: How local services support dementia preventative factors

| Life Stages | Preventable Risk Factors | Public Health Campaigns, Commissioned services, projects |
|--------------------|---------------------------------|---|
| Early Life | Less Education | Healthy Schools, Healthy Child Programme |
| | Smoking | Early intervention: Deliver targeted education to KS2 pupils on tobacco, smoking, alcohol, and drugs as an extension to PSHE offer. |
| Midlife 45 – 65 | Hypertension | Health Checks Programme/ Sport and Leisure GP referral Scheme/ Blood Pressure @ home project |
| | Obesity | Lifestyle changes, weight, diet, commissioned tier 2 weight management services |
| | Excessive Alcohol | Lifestyle changes/ Cranston, Wokingham - Cranstoun |
| | Peripheral hearing loss | Physical and community healthcare Berkshire Healthcare NHS Foundation Trust |
| | Traumatic Brain Injury | Physical and community healthcare Berkshire Healthcare NHS Foundation Trust |
| Later Life (65) | Smoking | Stoptober/ solutions for health/ Smoke free promotions |
| | Depression | Oxfordshire Mind / Recovery College/ Sport and Leisure GP referral Scheme |
| | Physical Activity | Sport and Leisure / Age UK |
| | Air Pollution | Climate team WBC |
| | Social Isolation | Oxfordshire Mind / Recovery College |
| | Diabetes | Sport and Leisure GP referral Scheme |

6.8.3 Local diagnosis, treatment, and support services

The table below summaries the local diagnosis, treatment, and support services available to people living with dementia and their carers. Further details about the services can be found in the appendix.

| Service type | Service name | Service provider | Description | Aimed at |
|-------------------|---|--|---|--|
| Support services | Wokingham Dementia Community Partnership (WDCP) | Wokingham Borough Council in partnership with other leading Voluntary Community Sector (VCS) organisations | Delivery of dementia interventions aimed to increase awareness and to ensure support access | People living with dementia and their carers |
| Support services | Dementia Access Alliance | Local private and public sector organisations, volunteers | Representing represent the views of people living with dementia and their carers and to take action to help improve the lives of those living with dementia locally | People living with dementia and their carers |
| Physical activity | | Wokingham Borough Council | Physical activity and exercise options available for people living with dementia through the WBC Sport and Leisure team. | People living with dementia |
| Physical activity | Dementia Tea Dance | Wokingham Borough Council | In Wokingham a Dementia Tea Dance takes place within the Mindful Health and Wellbeing Activities Programme | People living with dementia |
| Physical activity | Dementia walks | Age UK Berkshire | Dementia Friends/volunteers lead varied walks with up to 2 to 3 leaders at each walk. The sessions are also supported by dementia friendly organisations. Funded until September 2022 | People living with dementia and their carers |
| Support services | Multiple | Age UK Berkshire | Hospital transport; handy man service; dementia café; befriending; singing groups; maintenance cognitive stimulation therapy; carers group; one-to-one support ³ | People living with dementia aged 50+ |

³ The Age UK Berkshire service provides ongoing one-to-one support for people with memory loss or living with dementia and can give some respite to carers. This service costs £20 per hour and can be paid for by families, carers, and friends, as well as using Personal Budgets/Direct Payments from Adult Social Care, where these have been made available. Currently focused on West Berkshire and Reading, Age UK Berkshire may be able to offer this service in other parts of Berkshire by request.

| Service type | Service name | Service provider | Description | Aimed at |
|-------------------------|------------------------------|--|---|---|
| Support services | Multiple | Younger People Living With Dementia Berkshire | Admiral nurse; carers support groups; education and training; one to one support | People aged under 65 years of age living with dementia and their carers |
| Support services | Alzheimer's café | Wokingham Methodist Church | Wokingham Alzheimer's café is currently held every 2 weeks at Wokingham Methodist Church. It is a safe environment for people living with dementia and their carers to meet socially on a regular basis. Wokingham Dementia Care Advisory service attends the Alzheimer's café to offer advice and information as needed. | People living with dementia and their carers |
| Support services | Dementia café Reading Royals | Reading Football Club Community Trust and Age UK Berkshire | A memory café offers safe space for those living with dementia to have refreshments and conversations with others suffering from dementia as well as the opportunity to speak to qualified professionals. A memory café can provide advice and information for someone caring for a loved one living with dementia, supporting family members and carers are an important function of the cafés | People living with dementia and their carers |
| Diagnosis and treatment | Memory Service | Berkshire Healthcare NHS Foundation Trust | The Memory service provides an assessment of memory and other skills for those who show signs of dementia. Those subsequently diagnosed with dementia, can then be offered treatment and support for individuals and family/carers. Referral is via a person's GP Referral rates are increasing, and current waiting times are 15 weeks (March 2022) | Those showing signs of dementia |
| Support services | Memory Service | Berkshire Healthcare NHS Foundation Trust | 'Understanding Dementia Course' is offered to provide understanding and support someone recently diagnosed with dementia. The course provides information on local support including: | People recently diagnosed with dementia and their carers |

| Service type | Service name | Service provider | Description | Aimed at |
|--------------------|--|----------------------------|---|---|
| | | | <ul style="list-style-type: none"> • Transport • Local activities • Carer support | |
| Support services | Wokingham Dementia Care Advisory Service | Wokingham Borough Council | The Dementia Care Advisory Service provides advice and support to including listening; signposting; social opportunities; money and benefit advice; living well with dementia | People diagnosed with dementia The service is also available to their carers, families, and friends |
| Support for carers | Dementia Carer Group | Wokingham Methodist Church | A Dementia Carer group meets monthly at Wokingham Methodist church. Dementia carers are welcome as well as people living with dementia. Activities are available for those living with dementia. Wokingham Dementia Care Advisory service and TuVida carer support workers also attend the group to offer information and advice. | People living with dementia and their carers |
| Support for carers | Crossroads | Crossroads Care | Providing home-based respite breaks for unpaid carers and the people they care for. The service also supports people living alone with dementia in the community | People living with dementia and their carers |
| Support for carers | Multiple | TuVida | Support for carers and their families including care at home; day centres and groups; carer respite; carers hub; Wokingham Young Carers service | Carers and their families |

6.8.4 Local services gaps

6.8.4.1 Physical activity

- **Comments from Dementia Care Advisor - Wokingham Borough Council**
 - Younger people living with dementia are wanting to do more activities. There are less accessible physical activity provision for the age group 65-75 living with dementia
 - Older people's services have less physically active sessions available.
 - Previous provision has been in the form of gentle seated exercise sessions, or the tea dance mentioned earlier. A tea dance is considered by many living with dementia to be an older person's activity. A more inclusive dance aimed at younger people may be more appropriate.
 - A dementia swimming session has been suggested by people living with dementia.
- **Comments from Age UK Berkshire**
 - Essential that physical activities are dementia friendly
 - Few activities – over subscribed
 - To consider place-based approach as individuals are prepared to travel to activities

6.8.4.2 Primary care

Carers have reported that they have been unable to speak to a GP or health professional when worried about progression of dementia for patients they are caring for and how to better support them. Since the COVID-19 pandemic began they feel they are not receiving the time and care needed, and have raised concerns about medication checks and reviews not happening at 6 month or yearly intervals. A pathway is needed to give consistent advice.

- **Comments from Age UK Berkshire**
 - Berkshire West CCG are currently working to develop a Berkshire West Dementia Action Plan project with objectives focusing on ensuring people with dementia receive an appropriate annual health check from their GP.

6.8.4.3 Prevention

The NHS Health Check programme offers advice and support to help people aged 40-74 make changes that can reduce the risk of dementia (NHS, 2020). The programme does not currently address mental health problems. There is a clear need to increase knowledge of the risk factors associated with Vascular Dementia and to promote how positive lifestyle changes can make a difference, through public awareness and establishing dementia friendly communities (Department of Health, 2013).

Uptake of NHS Health Checks in Wokingham is very low. At the time of writing this needs assessment Wokingham Public Health Team were reviewing the health checks offer in Wokingham with a view to improving coverage.

6.9 Summary and discussion of the main findings

Risk factors: Lifestyle and physical health conditions

- Obesity prevalence has been lower than the regional and national averages but has seen a faster increase in Wokingham compared with the regional and national averages over the most recent period
- Prevalence of physical inactivity in Wokingham has been below the regional and national averages but has seen a rapid increase in the most recent period.
- Smoking rate declining and has remained significantly lower than national and regional averages.
- Health checks coverage is below national average with a significant declining trend.
- Lower alcohol-related admissions seen in Wokingham which has not been showing the upward trends seen at regional and national levels
- Stroke prevalence has been lower than national average but increasing trend has been observed over the most recent period
- Hypertension prevalence has been lower in Wokingham than national average but there has been an increasing trend over the most recent period
- Diabetes prevalence has been lower in Wokingham than national average but increasing trend over the most recent period
- CHD prevalence in Wokingham has also been lower than regional and national averages and declining slowly over the most recent period.

Though lifestyle risk factors are generally lower than national and regional averages, there likely to be significant inequalities as there are pockets of significant deprivation in affluent areas such as Wokingham. The general upwards trends in the lifestyle and physical health risk factors are likely increase the prevalence of dementia in the future given the increasing life expectancy.

Prevalence

Around 29–76% of people with dementia or probable dementia in primary care are estimated to be undiagnosed.

- Using the consensus estimates of population prevalence and the ONS 2020 mid-year population estimates, it is estimated 2,250 people aged 65 years or older in Wokingham were living with dementia in 2020, which was equivalent 7.4% (95% confidence interval 7.1% -7.7%) of the population in that age group. This may be an underestimate as the prevalence of many of the risk factors (e.g., stroke, hypertension, diabetes, and obesity) have been increasing.
- QOF prevalence (all-age) has been lower than regional and national averages and declining in Wokingham
- Recorded prevalence 65+ in Wokingham has been similar to regional and national averages – the trend was declining at the time of the needs assessment.

- On average 330 new cases of dementia are diagnosed in those aged 65 years or older in Wokingham each year. Generally declining new diagnosis rate trend was observed
- The estimated diagnosis rate in Wokingham was 58.9% in 2022, significantly lower than the England averages of 62.0%. There was significant decline over the most recent period with the likely COVID-19 impact evident in the trends at both local and national levels.
- There is a national a commitment to increase the number of people living with dementia who have a formal diagnosis. Measures to increase diagnosis will increase the overall prevalence and associated needs both at local and national levels.

Mental health comorbidities among those with dementia

There are higher levels of mental health comorbidities among people with dementia. Existing evidence shows that:

- Depression affects 20% to 32% of persons with dementia:
- Estimates of clinically significant anxiety among dementia sufferers are as high as 70% - higher for vascular and frontotemporal dementias
- Psychotic symptoms of delusions and hallucinations have been shown to be present in 18% and 14% respectively, among patients with dementia in a community-based cohort.

Living well

- Less than half of people living with dementia (47.8%) in Wokingham had their care plans reviewed in the preceding 12 months in 2020/21 but was significantly above both the South East and England averages of 34.4% and 39.7% respectively. There has been a significant decline in this indicator between 2019/20 and 2020/21 most likely due to the impact of COVID-19 – similar patterns were evident at both regional and national levels.
- The proportion of carers who reported they had “as much social contact as they would like” in Wokingham was 37.1% in 2018/19, comparable to the South East and England averages of 31.4% and 32.5% respectively. Though there has been an increase in this indicator between 2014/15 and 2018/19 from 33.8% to 37.1%, this was not statistically significant. However regional and national trends were downward overall
- Nationally carers are reporting increasing level of stress related to their caring roles with increasing proportions reporting significant financial difficulties. The average carer-reported quality of life score was 7.9 out of a possible 12 among Wokingham dementia carers in 2018/19 which was not statistically significantly different from the South East and England averages of 7.5 and 7.3 respectively. Though there was an upward trend in the reported scores between 2014/15 and 2018/19 the increase was not statistically significant.

The above indicate those living with dementia and their carers are having their needs reviewed and managed similar to national regional levels. However, there is a need

to improve timely review of care plans for those living with dementia and support their carers to have as much social contact as they would like to contribute to improving their quality of life.

Supporting well

- The bed capacity in Wokingham for dementia patients in 2020 was higher than the South East and England averages. The bed capacity in Wokingham has seen a statistically significant increase between 2018 and 2020 – similar increases in bed capacity at both regional and national levels.
- The proportion of beds suitable for a person with dementia (aged 65 years or older) rated as ‘good’ or ‘outstanding’ by the CQC is significantly better than the South East and England averages. Again, the rate has improved significantly between 2018 and 2020 - regional and national rates showed similar improvements
- In 2020, the CQC assessed 93.5% of Wokingham care and nursing homes which was significantly less than England average of 96.2% but similar to the South East average of 94.6%. There was a significant drop in Wokingham which was most likely due to the negative impact of the COVID-19 pandemic. Local partners should consider measures to support the CQC improve coverage of their assessment in Wokingham
- Admission rate for planned and unplanned care among those living dementia in Wokingham was significantly higher than the South East average but similar to the England average. There was a statistically significant rise in admission rate between 2016/17 and 2019/20 while at both regional and national levels there were downward trends
- Emergency hospital admission rate among dementia patients aged 65 years or older in Wokingham was significantly worse than the South East and England averages. There was a statistically significant increase in the rate between 2016/17 and 2019/20 and this was faster rate of increase compared with regional and national trends. There is a significant scope for reducing emergency admissions given the evidence base on underlying causes of emergency admission among dementia patients. Additionally, multiple emergency admissions at the end of life are disruptive and can impact negatively on a person’s quality of life (Nuffield Trust, 2022).
- Short-stay emergency admissions among Wokingham residents with dementia is significantly higher than the South East and England averages. There was a statistically significant increase in the short-stay emergency rate between 2016/17 and 2019/20. Though the regional and national trends were generally upward, the Wokingham rate of increase was faster. People with dementia can be more susceptible to changes in their surrounding environment, which can cause additional distress. Admissions to hospital, particularly ones of short duration, should be avoided where possible, for this population as this is also a measure of the quality of end-of-life care received by people living with dementia (Nuffield Trust, 2022).
- The ratio of inpatient service use to recorded dementia diagnoses provides an indication of the use of inpatient capacity to manage dementia cases; the

higher the ratio the lower the potential spare capacity to deal with any surge in inpatient care needs. The ratio in Wokingham was significantly higher than the South East and England averages. The ratio has increased significantly between 2016/17 and 2019/20 while the trends at both regional and national levels have remained flat. This pattern suggests there may be significant constraints on local inpatient spare capacity in the future if the recent upward trend in the local inpatient service use continues.

Dying well

- Death rate among people with dementia in Wokingham was significantly lower than the South East and England averages. Though the rate has declined in Wokingham between 2016 and 2019 from 885.3 to 714.8 per 100,000, the reduction was not statistically significant
- In 2019, 68.0% of deaths among those with dementia in Wokingham occurred in their usual places of residence, compared with the South East and England averages of 73.0% and 70.3% respectively though the differences were not statistically significant. The proportion declined from 75.1% in 2016 to 59.0% in 2018 but improved 68.0% in 2019 while regional and national averages showed improvements over the period
- It will be prudent for local partners to consider measures to increase the proportion of people living with dementia dying in their usual places of residence as this is an important quality measure of end-of-life care (Nuffield Trust, 2022).

6.10 Conclusions and recommendations

The findings of the needs assessment indicated there is a significant likelihood dementia prevalence will increase. The main drivers for the predicted increase are increasing prevalence of lifestyle risk factors such as obesity and physical inactivity, physical health condition risk factors such as diabetes, an ageing population as result of increasing life expectancy, and national policy aimed at improving diagnosis of dementia.

Lifestyle risk factors are largely modifiable, and it is recommended preventive measure a delivered at scale to reduce their prevalence and aim to reduce local inequalities.

Early diagnoses of physical health risk factors will ensure early management of these factors and reduce the risk of developing dementia. Existing data on physical health risk factors may not be complete potentially underestimating their prevalence as GP data, which is the main source of this data, may not include people who have not presented to them with the conditions of interest. It is recommended partners work to improve uptake of NHS Health checks and other routine health reviews to ensure early diagnoses of these conditions (e.g., hypertension and diabetes) for optimum management.

Local capacity to manage dementia patients was adequate at the time of the needs assessment but there were indications of the growing constraints on inpatient capacity as indicated by the increasing trends in ratio of inpatient service use to recorded dementia diagnoses which has been most likely driven by increasing

emergency and short-stay admissions. These patterns may be a reflection of the quality of the end-of-life care provision. The underlying causes of these admissions are potentially preventable. It is therefore recommended that partners work to identify and rectify any issues in the management of these patients with a view to reducing unplanned inpatient service use and improving the quality of the end-of-life care.

Deaths at the place of usual residence has declined over recent period preceding the development of this needs assessment. Again, this may be a reflection of the quality of personalised end-of-life care and it is recommended local partners work to understand the underlying factors influencing the trend and take appropriate measures to address any issues identified.

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6.12 Appendix 1. Dementia services

6.12.1 Wokingham Dementia Community Partnership (WDCP)

Wokingham Brough Council work in partnership with other leading Voluntary Community Sector (VCS) organisations to deliver prevention projects for specialist services. A new programme of funding has been made available for dementia interventions that can deliver programmes of delivery against specified criteria.

Key outcomes include:

- Increased awareness of dementia and Dementia-Friendly Wokingham is established
- Ensuring people living with dementia and carers receive the right support at the right time
- Ensuring people with low to moderate progression of dementia and their carers receive health and wellbeing support to prevent, reduce and delay the need for formal care and support
- Increased numbers of people with low to moderate level dementia and their carers from harder to reach communities are offered help and support to manage the condition

These outcomes will be beneficial for individuals living with dementia and carers and will support mental health outcomes. Delivery of the partnership begins January 2022.

6.12.2 Dementia Action Alliance

The Wokingham Dementia Action Alliance was formed in February 2014 by representatives from a diverse range of:

- Businesses
- Charities
- People living with dementia
- Shops

It aims to represent the views of people living with dementia and their carers and to take action to help improve the lives of those living with dementia locally. By overcoming obstacles and taking action to make Wokingham Borough dementia friendly the alliance aims to help people live well living with dementia in their own homes and community for longer (Wokingham Dementia Action Alliance, 2020)

Wokingham Dementia Action Alliance is currently on pause but will be delivered through WDCP, including recruitment for a Wokingham Dementia Co-ordinator. This post will drive return of meetings forward.

6.12.3 Physical Activity

Physical activity offers significant benefits to people living with dementia. Individuals can benefit from being active and enjoying activity such as walking and exercise sessions. In Wokingham pre-COVID-19 Physical activity and exercise options were available for people living with dementia through the WBC Sport and Leisure team. Activities include:

- Sessions of tennis/bowls etc
- Regular seated exercise sessions
- Sporting Memories sessions
- Dementia Swimming and exercise sessions for carers

Physical activity sessions and events with social opportunities are popular with those living with dementia. In Wokingham a Dementia Tea Dance takes place within the Mindful Health and Wellbeing Activities Programme, sessions are well attended and enjoyed by service users.

Dementia walks are run by Age UK Berkshire, they are available to individuals living in Berkshire. Those diagnosed in Wokingham can also access services. The dementia walks are funded until September 2022. Dementia Friends/volunteers lead varied walks with up to 2 to 3 leaders at each walk. The sessions are also supported by dementia friendly organisations. Participation at the walk is good with between 15-20 attending each month. See figure 3 & 4 posters below.

Figure 6.36: posters for Dementia Walks and Tea Dance



Source: Age UK Berkshire (2021)

Gaps/Opportunities identified

- Younger people living with dementia are wanting to do more activities. There less accessible physical activity provision for the age group 65-75 living with dementia
- Older people’s services have less physically active activities available.
- Previous provision has been in the form of gentle seated exercise sessions, or the tea dance mentioned earlier. A tea dance is considered by many living with dementia to be an older person’s activity. A more inclusive dance aimed at younger people may be more appropriate.

- A dementia swimming session has been suggested by people living with dementia.

Comments from Dementia Care Advisor WBC

Gaps/Opportunities identified

- Essential that physical activities are dementia friendly
- Few activities – over subscribed
- To consider place-based approach as individuals are prepared to travel to activities

Comments from Age UK Berkshire

6.12.4 Age UK Berkshire

Age UK Berkshire is a leading organisation providing integrated health and wellbeing services for older people across Berkshire. It is a local independent charity and part of the Age UK brand.

Age UK Berkshire believe that everyone can enjoy later life, they support and enable older people in a number of ways:

- To encourage choice and opportunity for older people
- To be a direct service provider of high-quality services for older people
- To ensure that older people are aware of, and have access to, the benefits to which they are entitled
- To advocate on behalf of older people
- To promote positive attitudes towards older people and ageing

Current activities include:

- Online Dementia café – and Face to Face Dementia Café
- Befriending sessions
- Memory lanes singing café
- Maintenance Cognitive Stimulation Therapy (MCST)
- Carers Group.

Figure 6.37: posters showing dementia café and singing café



Source: Age UK Berkshire (2021)

6.12.5 Younger people living with Dementia Berkshire (YPWD)

Traditional support services for those living with dementia are designed to support needs and outcomes for older adults which can mean access to activities for younger adults living with dementia can be limited. The YPWD (membership) group offers support to the 65-age group including:

- Admiral Nurse
- Carers Support Groups
- Education and Training
- One to one support
- Workshops

The YPWD model encourages carer respite throughout the working week, giving all carers the chance to take a break ([YPWD, 2020](#)).

6.12.6 Dementia one-to-one support

The Age UK Berkshire service provides ongoing one-to-one support for people with memory loss or living with dementia and can give some respite to carers.

This service is individually planned and implemented according to the service user's specific needs. Specially trained support workers offer one-to-one work with people living with dementia in their own homes or elsewhere according to their needs, interests, and ability, providing support, stimulation, and continuity. The service

complements those offered by other voluntary organisations rather than replacing them and works closely alongside the NHS and other health and social care services.

This service costs £20 per hour and can be paid for by families, carers, and friends, as well as using Personal Budgets/Direct Payments from Adult Social Care, where these have been made available.

6.12.7 Dementia cafés

6.12.7.1 Wokingham Alzheimer's café

Wokingham Alzheimer's café is a prominent dementia service in Wokingham which was established in 2015. Wokingham Alzheimer's café is currently held every 2 weeks at Wokingham Methodist Church. It is a safe environment for people living with dementia and their carers to meet socially on a regular basis.

Wokingham Dementia Care Advisory service attends the Alzheimer's café to offer advice and information as needed.

6.12.7.2 Dementia Café Reading Royals

A memory café offers safe space for those living with dementia to have refreshments and conversations with others suffering from dementia as well as the opportunity to speak to qualified professionals. A memory café can provide advice and information for someone caring for a loved one living with dementia, supporting family members and carers are an important function of the cafés. See Figure 6.38 for details about Dementia Cafe Reading Royals.

Figure 6.38: Dementia Cafe Reading Royals



Source: Age UK Berkshire (2021)

6.12.8 Memory Services

6.12.8.1 *Memory service | Berkshire Healthcare NHS Foundation Trust*

Difficulties with memory and concentration can be caused by many different things. However, a living with dementia early diagnosis can help with high quality of life and independence.

The Memory service provides an assessment of memory and other skills for those who show signs of dementia. Those subsequently diagnosed with dementia, can then be offered treatment and support for individuals and family/carers.

The Memory Service offers an appointment with a Mental Health Practitioner, Consultant Psychiatrists to assess individuals' memory and other skills.

To access the memory clinic individuals, need to be referred by their GP. At the first visit blood will be taken and a check over physically and consent gained.

The clinic offers a duty system which reviews the referral and checks an appropriate pathway of either Memory Clinic or the Community Mental Health Team. The Community Mental Health Team deal with more complex cases requiring more support. The Psychologist Service can offer carer support and counselling for relevant patients at a high level and with a more targeted therapeutic level of support.

Treatment options will be discussed including:

- Referral to Dementia Care Advisory Service'
- Medication (which will be reviewed by GP and memory clinic)
- Post-diagnostic support
- Cognitive stimulation therapy
- Educational programmes for your family and carers
- Brain scan
- Feedback appointment
- Formulate diagnosis
- 4-8 weeks later post diagnostic support (fills gap, carers can ask questions)
- CST online (4-5 groups) carer support essential (Pre COVID-19 face time)
- Understanding Dementia course 6-week online course (Pre COVID-19 face to face)
- Care plan

Participants all receive an acknowledgment letter – including signposting information to relevant activities and an appointment letter including carer's scale to assess stress, function, and wellbeing.

Memory Clinic referrals are on the increase with an estimate of 22.1% from 2019 and 36.1% from 2020. Current waiting times for the memory clinic are currently 15 weeks (March 2022) however this changes every month. (Memory Clinic, 2022).

'Understanding Dementia Course' is offered to provide understanding and support someone recently diagnosed with dementia.

The course provides information on local support including:

- Transport
- Local activities
- Carer support

6.12.9 Wokingham Dementia Care Advisory Service

The Dementia Care Advisory Service provides advice and support to people diagnosed with dementia. The service is also available to their carers, families, and friends.

The service is available to anyone living in Wokingham Borough with a dementia diagnosis.

- Dementia Care Advisors provide support by
- Listening to concerns and providing confidential support
- Providing a consistent point of contact
- Offering relevant and timely information
- Linking with Health and Social Services where necessary
- Providing opportunities to meet other people with dementia and carers
- Information on Local activities, groups, and carer support services
- Longer term planning, including legal issues
- Money matters and benefits
- Living well with dementia
- Taking a break

6.12.10 Carers

Dementia Carer Group: this is a Dementia Carers' group meets monthly at Wokingham Methodist church. Dementia carers are welcome as well as people living with dementia. Activities are available for those living with dementia. Wokingham Dementia Care Advisory service and TuVida carer support workers also attend the group to offer information and advice.

Crossroads: this is a local charity, home care provider, fund back me up scheme, register in emergency crossroads will step in, support medical appointments, home care, respite, sit in services (paid separate).

Wokingham Carers Hub: provide support, signposting, and newsletter for carers of all ages.

TuVida (Berkshire): this organisation supports carers and their families across Reading, West Berkshire, and Wokingham. Services include:

- Care at home: Individualised, home-based support that helps people requiring care to remain as independent as possible.
- Day centres and groups: A change of scenery for people receiving care support, as well as the opportunity to meet new people in a fun and relaxing environment.
- Carer respite: Temporary home care provision that enables periods of respite for carers.
- Carers Hub: Our Carers Hubs (currently available in Reading & West Berkshire, and in Wokingham) exist to support carers and make their lives easier in a

variety of ways – for example, by connecting them with other carers, or by providing free and confidential information and advice.

- Wokingham Young Carers Service: provides support for young people who look after members of their family. It enables young carers to take regular breaks from caring, make new friends, take part in fun activities, and access information and advice.