



Wolverhampton Joint Strategic Needs Assessment

**Dementia
2026**



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Executive summary

This Joint Strategic Needs Assessment (JSNA) provides an overview of health and wellbeing needs of Wolverhampton residents with dementia to inform and guide the action on dementia by partners across the city. We start with prevention of dementia, and then follow the course of a patient's journey of disease from diagnosis to support while living with the condition and through to planning for end of life. It outlines how services are currently working, who they are serving, and the views of professionals and the public on what is working well and what needs to improve.

We found that there is significant opportunity for prevention of dementia, with high rates of risk factors for dementia locally and disproportionate rates of mixed and vascular dementia. Once dementia is suspected, health and social care services deliver good quality care but long waiting lists create delays in access and some people are not engaged with services at all. This is partly due to unclear information provision, with residents struggling to know how to access the wide range of support across statutory services and Wolverhampton's active voluntary and community sector. Support is insufficiently proactive and structured, which represents a missed opportunity to prevent residents reaching a point of crisis before receiving the help they need. These issues are experienced unequally across the city and so targeted approaches are needed for groups including the financially insecure, ethnic minority communities and those with young onset dementia.

This JSNA has used a range of methods to build a comprehensive understanding of the experience of dementia in the city. It presents national epidemiological data alongside analysis of local health and social care service data to identify trends, gaps and inequalities. It incorporates findings from a survey of professionals working with people living with dementia to capture operational insight across the system. The perspectives of people with lived experience are integrated throughout and formed a key part of the basis for our findings. Finally, a literature review of national guidance and peer-reviewed research was undertaken to identify best practice in prevention, diagnosis, and post-diagnostic support pathways, providing the academic evidence base for the report's conclusions and recommendations.

Dementia is a progressive neurological disease affecting memory, cognition and behaviour. Around 3100 people in Wolverhampton are estimated to have dementia, and it is the single largest cause of death in the UK. The number of people over the age of 65 in Wolverhampton diagnosed with dementia is predicted to increase by 40% between 2025 and 2045.

The strongest theme emerging from professionals and residents in the City is that more support is needed throughout the process, from referral for diagnosis to conversation about end-of-life care. There are a wide range of voluntary and community organisations

in Wolverhampton supporting people with dementia, from the Wolves Foundation to Alzheimer's Society. Residents speak highly of community groups including dementia cafes and carers support groups, which are sources of community support and signposting resources. However, many patients and families report a gap in support after diagnosis, and that there is nowhere to go for help. This is in part due to information about service access not getting to the people who need it in an easily understood form or at the right point in their diagnosis journey, although this can also reflect a lack of available support.

Support is most valued when it is provided proactively before the point of crisis. One example of good practice in this area is the City's high rate of annual dementia reviews in primary care, which give opportunities for proactive education and advance planning. Commissioned services such as Admiral Nursing and Dementia Connect provide highly valued clinical and social support respectively. However, these services have a limited capacity and require people to know where to seek help. Long waiting lists for diagnosis and other services compound the need for support. Across the system there remain gaps in understanding about how post-diagnostic support should be structured to prevent crisis, and further insight is needed to determine what approaches are most effective and acceptable to residents.

Early conversations are also needed to prepare for deteriorations in health, as we found that residents often do not have the opportunity to plan in advance. This is sometimes due to patients' and families' reluctance to discuss issues around death and dying. We found that partners could do more to initiate these discussions in a proactive, structured way, for instance by ensuring that annual care reviews address planning for end of life. The absence of these discussions in advance can lead to difficult decisions being made in crisis situations, and undue stress put onto family, friends and carers.

Most people living with dementia in Wolverhampton are cared for by family and friends, which can be an extremely rewarding experience. However, the requirements of caring can have significant impacts on carers' physical and mental health when adequate help is not in place. In Wolverhampton, 42% of unpaid carers for people with dementia report providing over one hundred hours of care per week, yet many have not received a Carer's Assessment and report limited awareness of available support. The consequences of this gap are substantial: over half of carers report feeling depressed, and one in three report deterioration in their physical health, which in turn affects the sustainability of care. Health and social care professionals identified that lack of access to respite care and dementia-specific training contributes to carer burnout, and evidence shows that timely respite can improve quality of life for both carers and the people they support. These findings highlight a need for system-wide action to ensure that support for carers is proactive, accessible, and fit for purpose.

The need for support can begin before diagnosis, as long wait times mean support is needed before assessment. Dementia diagnoses are almost always made by the specialist memory assessment service, which provides a high standard of care according to patient feedback. However, in July 2025 over 50% of patients in Wolverhampton were waiting more than 18 weeks for an initial assessment¹, substantially exceeding the 6 week target set by NICE.

Hospital admissions for acute physical health problems have a particular importance for people with dementia, as admission can contribute to a decline in functioning and difficulties returning home to independent living. We found that people with dementia spent over 50% longer in New Cross A&E than patients of a similar age, showing that dementia patients are systematically different from the population as a whole and require specialised support. Barriers to data access limited our ability to understand the drivers behind these patterns, and so further work is needed to understand why people with dementia present to hospital, what specific obstacles delay their discharge, and what the training needs of staff are.

People with dementia and their families reported difficulties dealing with different organisations due to receiving conflicting or incomplete information, causing confusion and additional stress at key points in the care pathway. Professionals identified that variations in the quality of information shared between organisations caused delays and misalignment of treatment goals between different teams caring for the same patient. Clear, coordinated communication is essential to ensure that all partners are working toward the same goals and providing consistent messages.

Communications and the provision of support need to be appropriately tailored to groups of patients who face systematic barriers. People with young onset dementia often encounter services designed around older adults, meaning that their distinct needs, such as employment or parenting responsibilities, are not adequately met. Residents from ethnic minority communities have reported that information resources and support offers are not always culturally or linguistically appropriate, contributing to difficulties engaging with services. There is an opportunity for partners to build on research led by the University of Wolverhampton which has engaged diverse communities in understanding their experiences of dementia, and has co-produced culturally appropriate information resources that reflect the needs of local residents. Financial insecurity is another important cause of inequity in access to support, as some forms of respite care and community activities require payment.

Another important barrier to engaging in community activities is that physical and digital environments are not consistently supportive of people living with dementia and their

¹ The Memory Assessment Service has been restructured to a Black Country wide footprint, so more recent waiting list data is not available specific to Wolverhampton

families. Residents raised issues including limited accessible parking and reliance on digital platforms and apps to access services. Public and service environments can also be difficult to navigate where lighting is poor, spaces are noisy, signage is unclear, or toilets and quiet areas are not easily accessible. Examples of dementia-friendly design include good lighting, clear signage, accessible toilets, quiet spaces, and parks with clear paths and regular seating. These adaptations can support independence, reduce anxiety and enable people with dementia to remain engaged in their communities.

Evidence shows that 45% of dementia cases are due to preventable causes, so there is an opportunity for action to reduce the number of future dementia cases across the city. The proportion of dementia cases caused by vascular disease (vascular dementia and mixed dementia) is more than three times higher in Wolverhampton compared to estimated national prevalence rates (79% vs 25%). This shows the need for action on high rates of cardiovascular risk factors for dementia such as smoking, alcohol-related disease and physical inactivity.

Overall, these findings demonstrate the need for urgent, targeted action across the system on prevention, diagnosis, post-diagnostic support, hospital care, information sharing, and carers support. Recommendations for action follow below, and these will action plan for implementation is laid out in the Dementia Strategy.

This JSNA would not have been possible without the commitment of partners across the city to improve care and support for people with dementia and their families. We would like to acknowledge the work of the following organisations in jointly producing this work: Alzheimer's Society, Dementia Action Alliance, Black Country Healthcare NHS Foundation Trust, Black Country Integrated Care Board, Public Health, Adult Social Care, and University of Wolverhampton.

Commented [IH1]: Isaac to add in environment

Commented [IH2]: ?to include adult social care and public health separately

Recommendations

- I. In response to Wolverhampton's disproportionately high burden of vascular and mixed dementia, dementia prevention should be embedded into commissioned services addressing cardiovascular risk. This includes services for smoking cessation, alcohol misuse and NHS health checks among others. Services should provide staff delivering lifestyle services with training on dementia prevention messaging, and that the provision of dementia prevention education is monitored and reported.
- II. Statutory partners should work closely with the DAA to promote dementia education among the community, address stigma, and facilitate dementia friendly environments.
- III. Partners should commission and jointly implement a clear and consistent pre-diagnostic support pathway for patients and carers awaiting diagnostic assessment. All patients and families should receive standardised information about the commissioned support services available to them at, or soon after, the time of referral. All partners should be enabled to provide accessible signposting information including contact details to patients and carers on demand. Further work is needed to identify how to make support more accessible and equitable; this should evaluate an opt-out referral or a proactive check-in call depending on resources available.
- IV. Information on sources of social support should be jointly redeveloped in collaboration with carers and people with dementia to maximise accessibility. Information should be provided in multiple formats, and partners should be mindful of the diverse needs of different communities in the support that is provided. Information should be in a form that is easy for frontline staff to share with patients. It should be clearly outlined where services are free to access.
- V. Partners across health and social care should consider a single point of access "care coordinator" model for support across the city. This is identified as best practice to promote inter-agency communication and continuity of care.
- VI. Partners across health and social care should ensure that Carers support continues to be prioritised as the Adult Social Care service is reorganised. Support should include outreach to carers who have not received an assessment; training and education for carers specific to dementia; and ensuring availability of respite care.
- VII. Partners should work to further understand the unique needs of patients with Young Onset Dementia, particularly around employment, caring responsibilities

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Commented [IH4]: Needs to go out to public health teams for review

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Commented [IH11]: Partners across health and adult social care. (GP contract quality incentive scheme)

and social isolation. Patients and families should be assured of access to bespoke services tailored to the specific needs of this stage in the life-course.

- VIII. Partners should work to strengthen the cultural appropriateness of support for ethnic minority communities. Statutory services should ensure that information is provided in formats that meet different literacy and communication needs. This should include co-designing materials and pathways with voluntary and community organisations that have established trust, cultural insight and language expertise.
- IX. Information sharing between organisations must be improved to enable all partners to be working towards an aligned set of goals with the patient at the centre. Information on referral to specialist services must be provided in a structured format, and specialist services must share clinical information with health and social care partners.
- X. Partners to complete service mapping exercise to understand the journey of people with dementia and their carers. This information should be shared with patients so that they can understand the available services. More needs to be understood about crisis prevention and intervention, including the need for structured post-diagnostic support before crisis occurs.
- XI. Partners should work to maximise patient autonomy in end-of-life care through the use of advance care plans. Annual care reviews should be leveraged to facilitate proactive conversations about end-of-life care while patients have capacity for these decisions. To enable this, services will need to ensure that patients and families understand the progression of dementia.
- XII. Partners should review the need for dementia-specific training for across the system, ensuring that the level of training is matched to the role.
- XIII. Partners should seek to better understand the experience and outcomes of dementia patients in acute care. This should involve examining why dementia patients present to hospital, reviewing key care quality indicators and identifying barriers to effective discharge.

Action plan

This Joint Strategic Needs Assessment (JSNA) has been developed alongside the Wolverhampton integrated dementia strategy 2025-29. The action plan and performance metrics for the implementation of the findings of this JSNA incorporated in the dementia strategy and subsequent action plan. Implementation will be overseen by the Dementia steering group, chaired by Black Country ICB.

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Purpose

The Dementia JSNA is a systematic review of the health and wellbeing needs of Wolverhampton residents with dementia. It provides an up-to-date evidence base alongside the Wolverhampton dementia joint strategy action plan. This work will lead to priorities for action agreed between partners that will improve health and wellbeing outcomes and reduce health inequalities for residents with dementia.

Scope

This JSNA will be focussed on the health and care needs of Wolverhampton residents with dementia, and on assets within the city relevant to living with dementia. This JSNA will:

- Review the current epidemiology of dementia in Wolverhampton in comparison to the regional and national picture.
- Present and analyse health service and social care data to understand system activity, outcomes, and inequalities across the patient journey. This will cover all stages from referral and diagnosis through to hospital care, community services, social care use, and end-of-life care.
- Assess the usage and provision of commissioned support services for people with dementia, including dementia connect to identify patterns, gaps, and areas of unmet need.
- Review the evidence base for dementia care, ensuring that our services are in line with national guidance.
- Evaluate the patient experience through describing the findings of the Black Country ICB patient insights survey

Governance

The JSNA task and finish group will sit under the Wolverhampton Joint Dementia Commissioning Group, which reports into the Integrated Commissioning Committee. Direction and outcomes will be taken and shared from these groups, and the final report will be taken to Health and Wellbeing Together board for approval.

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Clinical background

What is Dementia and what is the impact of Dementia?

World Health Organization (WHO) define Dementia as ‘a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.’(1)

Dementia is one of the world’s major causes of disability and dependency in older people, and is the leading cause of death in the UK.(2) It has an impact on the quality of life of not only those that have Dementia, but of their families and carers too. The impact on carers and family can be physical, psychological, social and economic. There is often a lack of awareness and understanding of Dementia, which can result in stigmatisation of the disease and barriers to care and diagnosis. Worldwide, the number of people with Dementia is estimated to triple by 2050. The cost of dementia to the UK is estimated at £42 billion.(1,3,4)

Types of Dementia

Alzheimer’s Disease

Alzheimer’s disease is the most common cause of dementia, comprising 60% of dementia cases in the UK. There are thought to be more than 520,000 people in the UK with Alzheimer’s disease.(5) The disease causes proteins to build up in the brain to produce structures called plaques and tangles, causing the loss of connections between nerve cells, eventually leading to the death of nerve cells and loss of brain tissue. Alzheimer’s disease is a progressive disease, which means that over time, more parts of the brain are damaged.

Most people who develop Alzheimer’s disease will develop it after the age of 65, however it can affect people before reaching the age of 65. This is known as early onset Alzheimer’s disease, which is often reported under the umbrella term ‘early onset dementia’. There are around 70,800 people with early onset dementia in the UK.(4) Age is the greatest risk factor for Alzheimer’s disease. Above the age of 65, a person’s risk of developing dementia doubles every 5 years. There are about twice as many females as males who have Alzheimer’s disease, for which the reasons are not fully understood. This observation is not fully explained by the fact that women live longer than men on average. Genetics plays a part in increasing the risk of developing Alzheimer’s disease, but genetic testing does not currently play a large role in treatment.

Vascular Dementia

Vascular dementia is the second most common type of dementia comprising 15 to 30% of cases in the UK and affecting around 180,000 people in the UK.⁽⁶⁾ Vascular dementia is caused by disruption in blood supply to the brain. This disruption is due to diseased blood vessels, leading to the blood vessels leaking or becoming blocked and causing brain cells to die. The death of these brain cells brings about the symptoms which are characteristic of dementia. Vascular dementia can develop following a stroke. A stroke occurs when blood supply to the brain is suddenly cut off, due to a blood vessel in the brain either narrowing or being blocked by a clot. This reduces the oxygen supplied to the brain and leads to the death of brain tissue. The severity of strokes depend on where the blocked vessel is and how long the disruption of blood supply is. Around 20% of people who have a stroke will develop dementia within the following six months.

Vascular dementia can be single-infarct (caused by a single stroke), or it can be multi-infarct (caused by multiple smaller strokes). An infarct is an area of brain tissue that has died due disruption of blood supply to the brain. It can also be subcortical, caused by diseases of the very small blood vessels that lie deep in the brain, which cause them the vessel walls to thicken and vessels to become stiff and twisted. This causes damage to the nerve fibres that carry signals around the brain (white matter). This process can also cause small infarcts around the base of the brain. Diseases of small vessels develop much deeper in the brain, compared to the damage caused by many strokes, therefore the symptoms may differ from stroke-related dementia.

Mixed Dementia

Around 10% of people with dementia in the UK are diagnosed with mixed dementia, although recent research suggests the true proportion may be higher. Mixed dementia commonly means that both Alzheimer's disease and vascular dementia have caused the dementia although other rarer combinations are possible. Symptoms of mixed dementia can vary between the symptoms of Alzheimer's disease and vascular dementia. While Alzheimer's disease, vascular dementia and mixed dementia account for the majority of prevalence, other significant subtypes include Dementia with Lewy Bodies, Frontotemporal Dementia, and Parkinson's Disease Dementia. Although individually less common, these types often require more specialised clinical pathways and integrated social care support due to their complex symptoms.

Risk factors

Modifiable lifestyle factors and preventable medical conditions are estimated to cause 45% of dementia cases. This creates a large opportunity for preventative action throughout the life course to substantially reduce risk of dementia. The diagram below, taken from the Lancet commission on dementia 2024,⁽⁷⁾ describes the areas where action is needed to reduce risk of dementia.

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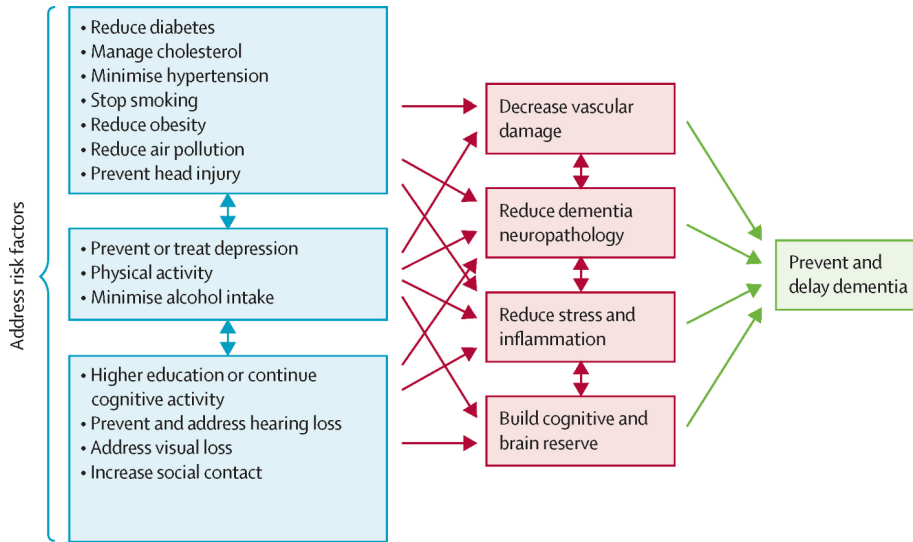
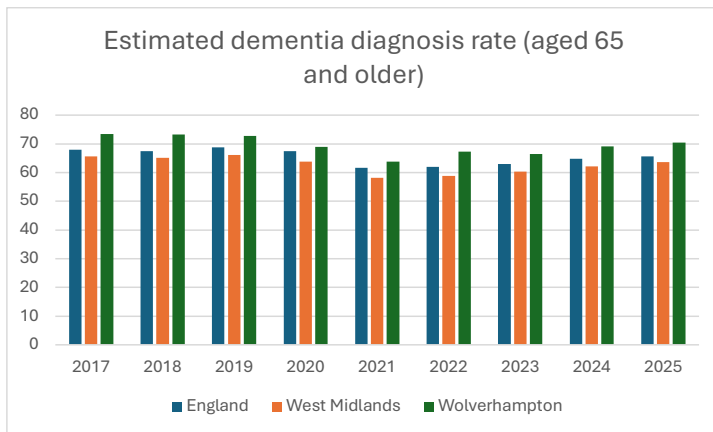


Figure 1 -taken from the Lancet commission on Dementia 2024 (5)

Epidemiological profile of dementia in Wolverhampton



Source: Fingertips PHE

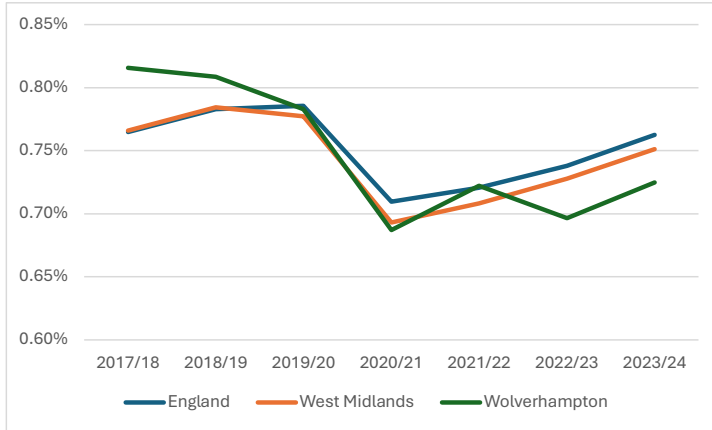
Dementia diagnosis rate (DDR) is calculated by comparing recorded diagnoses of dementia to estimated dementia prevalence based on the age and sex profile of an area.² Wolverhampton's rate has consistently exceeded the national average. However, rates have not recovered to pre-covid levels and there are still a significant number of residents living with dementia who do not have a formal diagnosis. In November 2023, NHS modelling estimated that there are around 3064 people with dementia in the city, compared with 2150 who are currently diagnosed. Under-diagnosis limits access to early support, carer help, and care planning.

Commented [KW16]: worth saying in lay terms what this is first

Commented [IH17]: Suggest: is above the national average, but an estimated 30% remain undiagnosed.

² DDR should be interpreted with caution as it is calculated using expected prevalence estimates based on research in areas that differ from Wolverhampton's demographic and socioeconomic profile. It is based on evidence from 2011, so in the context of falling incidence rates, estimates will be less accurate with time.

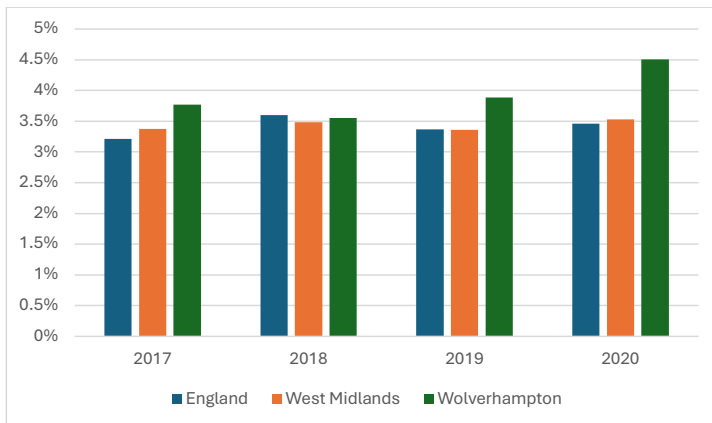
Figure 2 - Prevalence of dementia (QOF data)



Source: Fingertips PHE

This chart presents the Quality and Outcomes Framework (QOF) prevalence of dementia. The data refers to the proportion of individuals diagnosed with dementia, as listed on GP practice registers, relative to the total number of people (of all ages) registered at each practice. Wolverhampton's dementia prevalence was consistently above national and regional averages from 2017/18 to 2019/20. A dip in 2020/21 aligns with pandemic-related disruptions. Since then, rates have not recovered to pre-pandemic levels and are below national levels.

Figure 3 - Dementia (under 65 years) as a proportion of total dementia (all ages) per 100



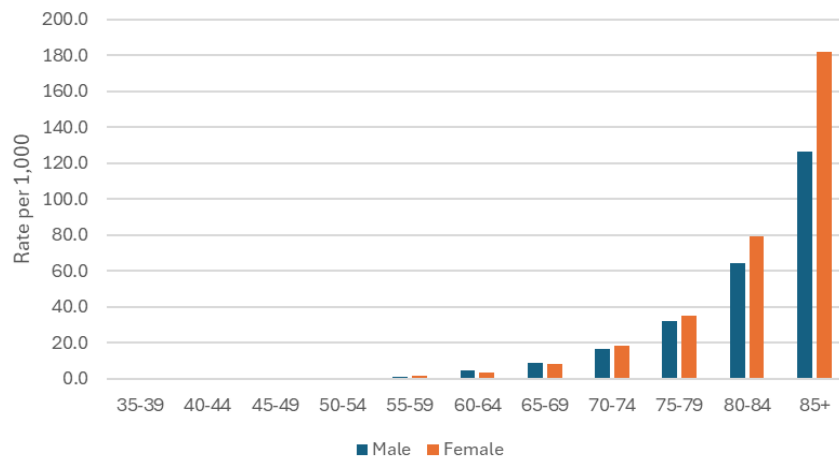
Source: Fingertips PHE

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The proportion of people with dementia under the age of 65 is calculated by dividing the number of individuals in this age group recorded on GP practice registers of dementia by the total number of people with dementia (of all ages) registered at each practice. Young onset dementia has historically been diagnosed in Wolverhampton at rates above the national average. This data is only available to 2020.

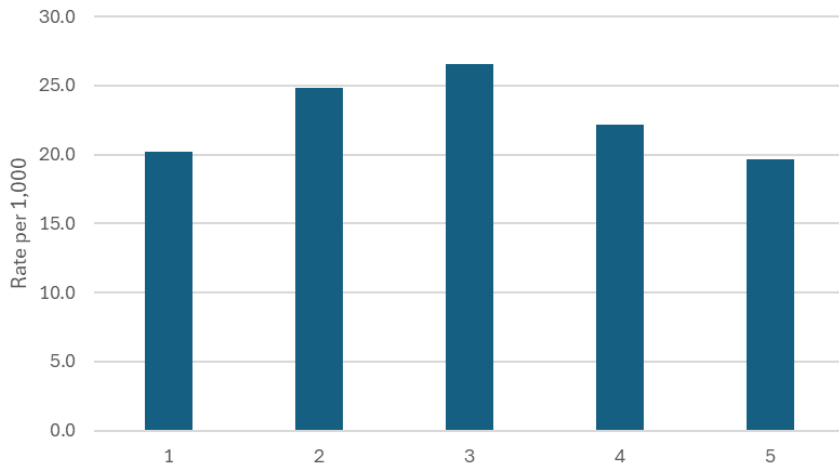
Primary care data

Figure 4 - Prevalence of dementia by age and gender



The figures in this section have been produced using data from the primary care electronic record (EMIS) in Wolverhampton. Across the city around 2150 over 65s are diagnosed with dementia on the primary care record, which represents an approximate value of 5% for this age cohort. Age is the most significant risk factor for dementia, as seen in the figure. A higher proportion of older adults are female compared to the general population, and older women are at higher risk of dementia compared to men.(7)

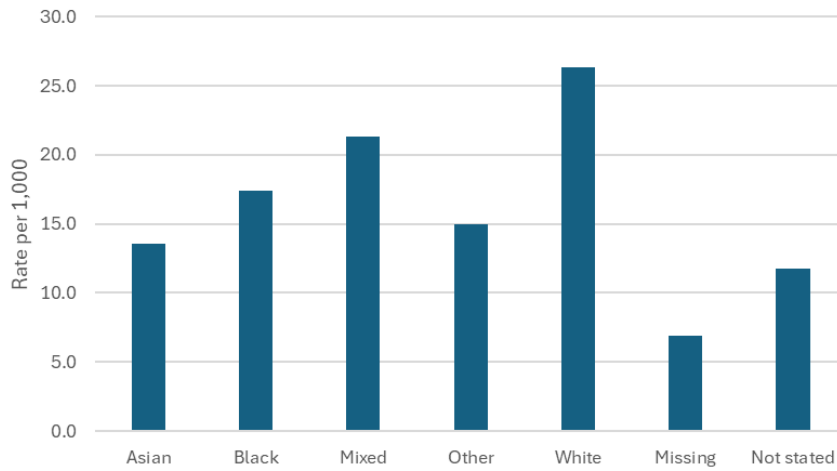
Figure 5 - Dementia prevalence by IMD quintile in residents over age 50



Nationally, dementia occurs at higher rates in more deprived areas.(8) Our local data shows a different picture, with the highest rates in the middle income quintiles. This could be due to a combination of early mortality in the most deprived groups, a younger age profile within the most deprived groups, and the locations of care homes within the city.

Commented [KW18]: have you considered the locations of care homes as confounding factor?

Figure 6 - Dementia prevalence by ethnicity in residents over age 50



The highest rates of dementia are seen in the white ethnic group, which aligns with the pattern in the national data.³ Nationally, people in the Asian ethnic group have the second rates of diagnosis, whereas in Wolverhampton the Mixed group is second highest. It is important to note that ethnicity recording is inconsistent across primary care, so this data should be interpreted with caution.

Primary care in Wolverhampton outperforms the regional and national rates of dementia patients having had a care plan review in the last 12 months. In Wolverhampton, 79% of patients had a care plan review in the 2024/25 year, against 73% nationally and 58% in the Black Country.

Commented [KW19]: this is for all 50+ and the White group has a higher % in the very old age ranges, is that a factor?

³ There is likely to be a residual confounding effect of age between the groups, even after stratification. However, this pattern is replicated in both national and age-adjusted data.

Population projection

According to data from the Projecting Older People Population Information System (POPPI)¹, The number of people aged 65 or over in Wolverhampton is expected to increase from 45,500 in 2025 to 57,800 in 2045. The number of over 65s living in a care home is predicted to increase from 1,324 in 2025 to 1,829 in 2045, a 38% increase.

The population aged 65 and over predicted to have dementia is predicted to increase from 3,247 in 2025 to 4,568 in 2045, a 40% increase.

Commented [IH20]: This might be a good place for a graphic - speak to design team

1. Institute of Public Care (IPC) & Office for National Statistics (ONS). (2022 population projections). *Projecting Older People Population Information (POPPI)*. Retrieved from <https://www.poppi.org.uk/>

Description of current services

Full mapping of the care pathway for dementia can be found in [Appendix 2](#).

Residents who have concerns about their memory present to their GP for assessment. People over 50 with suspected cognitive impairment are referred to the Memory Assessment Service (MAS), under the Black Country Healthcare Foundation Trust (BCHFT). Dementia diagnoses are almost always made by MAS in Wolverhampton, but can also be made by geriatricians in the acute trust. GPs can diagnose patients in care homes using the DIADEM memory assessment tool, but this is not widely used.

MAS provide information about dementia on diagnosis and create a care plan for each patient. The care plan may include medication, and referral to [support services](#) such as Older Adults Therapeutic Service (OATS) for both therapeutic needs and Dementia Connect for social needs. Patients will then be discharged back to primary care, although medication continues to be managed by BCHFT.

Primary care undertakes an annual dementia review with patients and carers, which may involve discussion of advance care planning, signposting to carers support and addressing wider health issues.

There are a range of post-diagnostic [support services](#) in Wolverhampton. Dementia Connect provide a signposting service to direct people towards support in the community, and provides telephone and in-person support consultations. The dementia services directory contains written information on local sources of support. The admiral nursing service provides specialist clinical support to residents and carers who have higher levels of need. Community palliative care is provided by Compton care.

Commented [IH21]: Get pathway map and then write into paragraph here

Black Country Healthcare Foundation Trust

Black Country Healthcare Foundation Trust have provided stratified data on referrals, diagnoses and diagnosis type, which has been recorded over a two year period 1st August 2023 - 31st July 2025.

Data by Age

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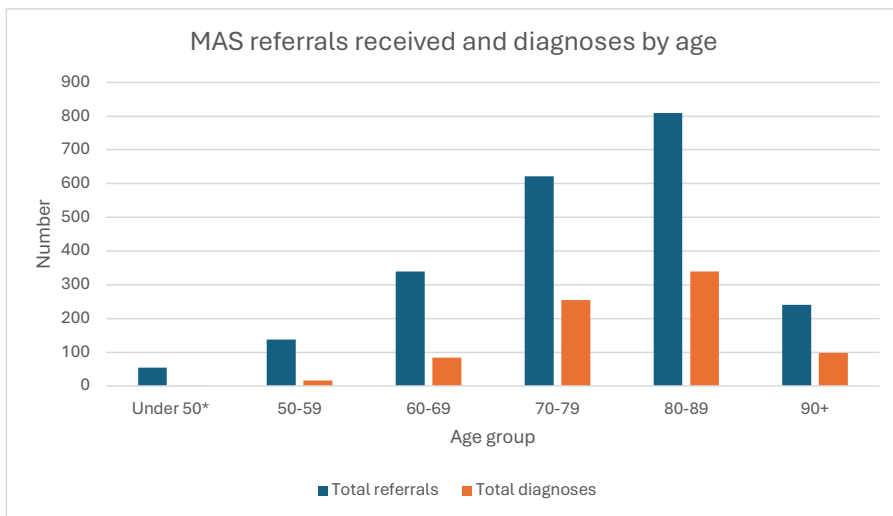


Figure 7 - Referrals received and diagnosis made at the Memory assessment clinic, Wolverhampton

Both the number of referrals received, and the number of diagnoses made increase with increasing age. Referrals of patients at younger ages are less likely to result in a positive diagnosis of dementia.

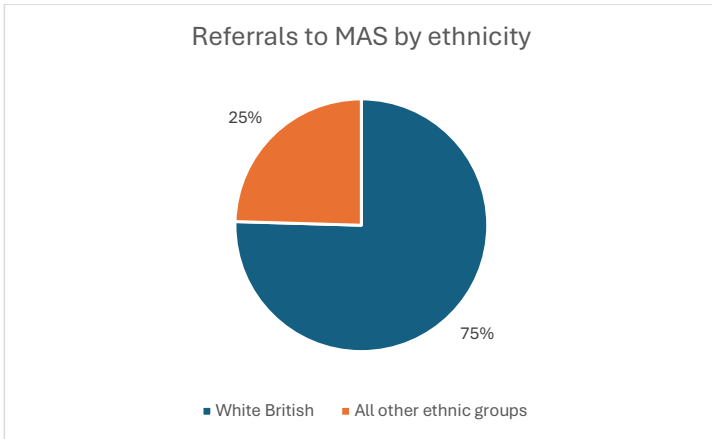
Data by gender

These data show that referrals to MAS are 60% female and 40% male, with a similar proportion on the waiting list. Dementia diagnoses are 59% female and 41% male, which is in line with the national picture.

Data by ethnicity

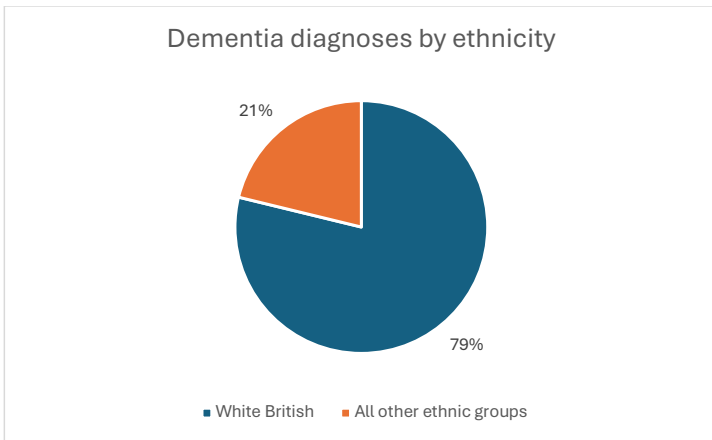
Commented [IH23]: I have asked for aggregated data from BCHFT, which should partially solve this problem of suppression

Due to the format of data, it has only been possible to analyse the data as White British and all other ethnic groups. More detailed data was requested but not received.



Commented [KW24]: suggest changing the language - how about "all other ethnic groups" rather than BAME.

Excluding those of unknown ethnicity, 75% of referrals to MAS were for White British patients. Data from the 2021 census shows that 77% of over 65s in Wolverhampton are from the white British ethnic group (most dementia referrals are made for patients over age 65). Therefore, we do not have evidence that ethnic minority patients are less likely to be referred for assessment for dementia.



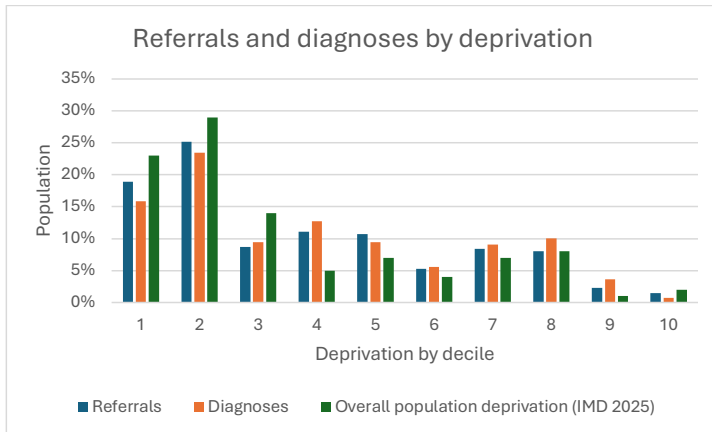
Dementia diagnosis rates by ethnicity are broadly in line with the expected ethnic breakdown of the population, at 21% of all diagnoses. This is significant because concerns have been raised around the cultural appropriateness of dementia diagnoses.

Clinicians at MAS use a range of diagnostic tools to accommodate patients with diverse needs: "[We use] MoCA (Montreal Cognitive Assessment) if someone is blind and RUDAS (Rowland Universal Dementia Assessment Scale) for people whose first language is not English. ACE 111 (Addenbrooke's Cognitive Examination-III) also comes

in different languages if needed and we use a Mini ACE version if someone can't engage with a full ACE 111.”(personal communication, Dr Khalid, 2025)

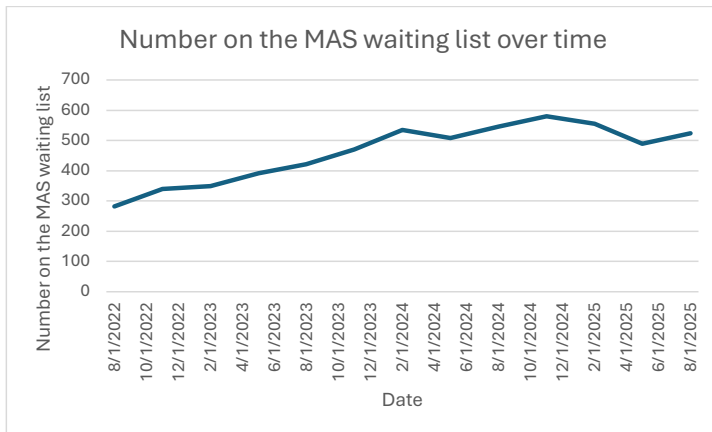
Commented [IH25]: Check with Rachel Name of clinician ?Dr Khalid

Deprivation



BCHF data show that overall, referrals and diagnoses are roughly in line with the population levels of deprivation. Lower levels of referrals and diagnoses are seen in more deprived groups, and higher numbers in the mid and low deprivation groups. This is likely to be a confounding effect of higher numbers of younger people in more deprived groups in Wolverhampton.

Waiting list



The number of people on the MAS waiting list increased throughout 2023, and has been relatively stable across 2024 and 2025. The population on the waiting list is broadly

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representative of the referred and diagnosed populations in gender, ethnicity and deprivation markers.

Increasingly long wait times for assessment have been raised as an issue during engagement with professionals. During this time, patients report a need for support which is not being met.

The data below show how long patients had been on the waiting list for MAS services on 15/7/25. We can see that many patients are waiting longer than the recommended 6 weeks for assessment, with the majority waiting over 18 weeks. It is important to note that MAS has now been restructured to a Black Country wide footprint, so wait list data will look different going forward.

Table 1 - Wait times for assessment at MAS Wolverhampton, 15/7/25

Time on waiting list	0 – 8 weeks	9 – 12 weeks	13 – 17 weeks	Over 18 weeks	Total
Number of patients	168	39	43	259	509

There are several external factors which have contributed to the increasing waiting lists. There has been a substantial increase in annual referrals to MAS services over the last five years. Waiting times have not decreased since the pause in service due to Covid-19. In the absence of an increase in funded capacity, the service has not found a way to reduce waiting times.

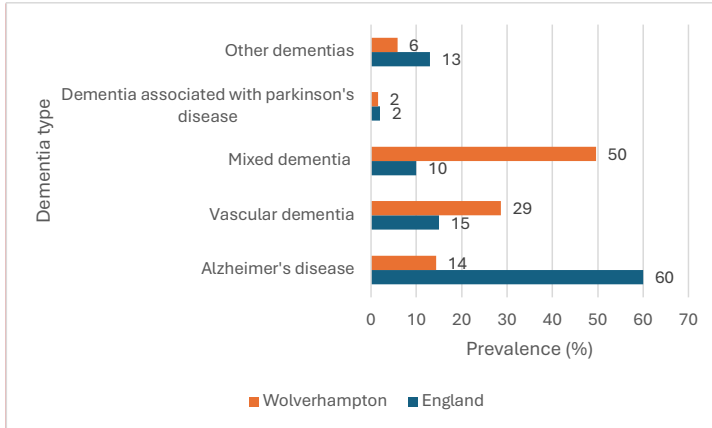
MAS has re-organised from predominantly home visit assessments towards a clinic-based model, which has increased the number of patients clinicians are able to assess in a session. The service has changed recruitment criteria to allow recruitment of nurse specialists with a background in general nursing, therefore accessing a wider pool of expertise.

Diagnosis type

Using further data provided by BCHFT, we can see that in the 18 month period from 01/01/2024 to 15/07/25, there were 516 dementia diagnoses made in Wolverhampton. Of these, 17 were young onset dementia, defined as onset in patients aged 64 and under.

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Figure 8 – proportion of all diagnoses of Dementia by subtype

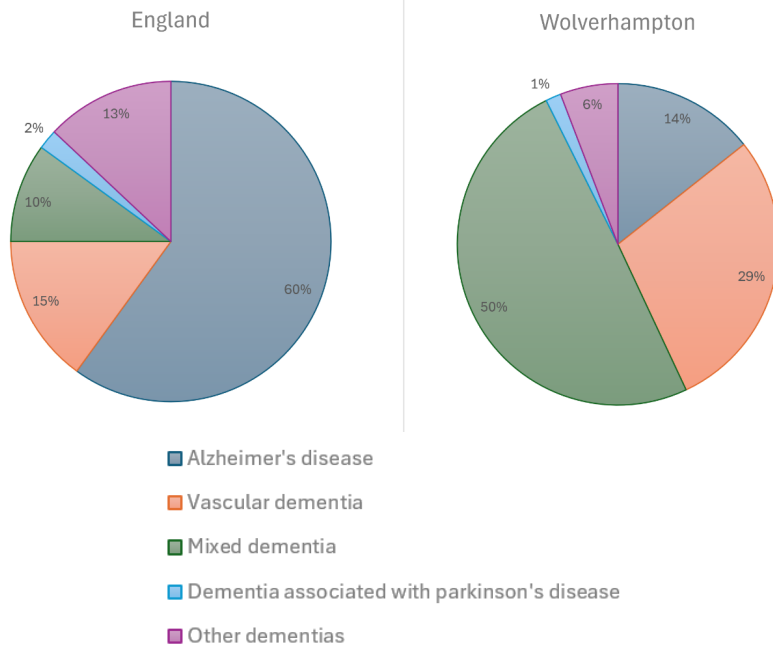


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Diagnosis types are explained further under [Clinical Background](#). Mixed dementia has a high prevalence in Wolverhampton. According to the diagnosis coding this category signifies patients with Alzheimer's disease and an additional type of dementia, most commonly vascular dementia. The rate of vascular dementia in the literature is 15 – 20% with some sources quoting up to 30%.⁽⁹⁾ Mixed dementia is estimated at 10%, although recent research suggests that mixed dementia is much more common than previously thought.⁽¹⁰⁾

In Wolverhampton, vascular dementia accounts for 29% of diagnoses and likely contributes greatly to the number of mixed dementia diagnoses (50%), so we have evidence that the burden of vascular dementia in the City of Wolverhampton is exceptionally high. This highlights the need for interventions to address cardiovascular risk factors to reduce incidence of dementia.

Figure 9 - proportion of all diagnoses of Dementia by subtype, as pie charts

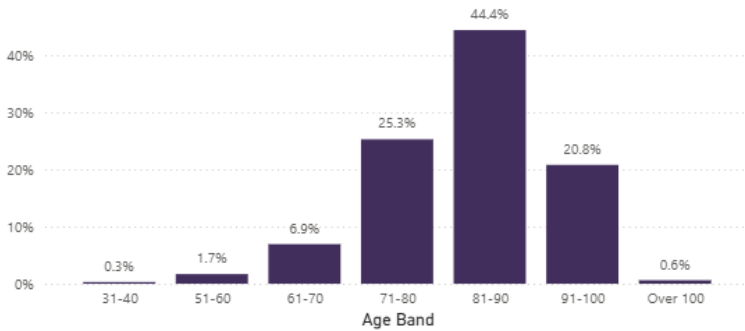


Social care provision

The majority of people with dementia do not need permanent support from social services, instead receiving assistance from networks of family and friends, temporary respite care and self-funded care. Out of an estimated 3100 people who have dementia in Wolverhampton, 621 people have an “active service agreement”, meaning that they receive social services support funded by the council. This support includes help with personal care and with activities of daily living.

Women receive 68% of dementia service agreements. Women make up 62% of all diagnosed cases, but are over-represented in the older age groups which are more likely to require formal care.

Figure 10 - Service agreements by age



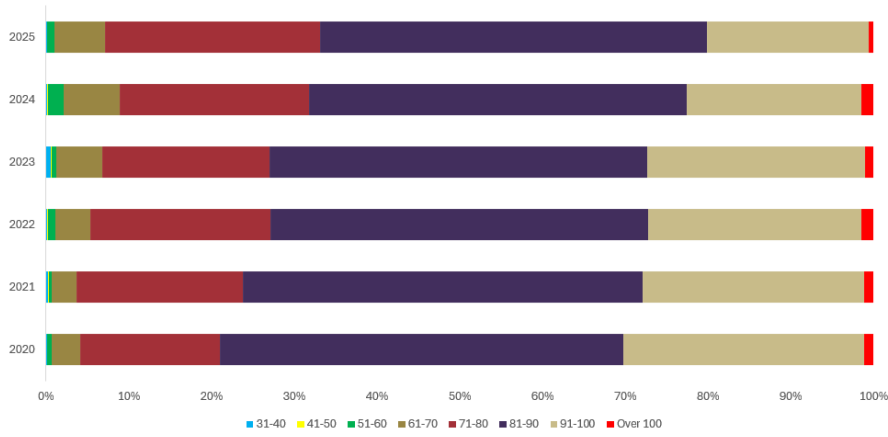
Age is the strongest risk factor for developing dementia, and we have found that 96% of active service agreements are for residents over the age of 65 as shown above. However, there has been an increase in the proportion of service agreements for younger residents, as seen in the figure below. Service agreements in those aged 61-70 have gone from 3.5% of the total to 6.2% over the last five years; service agreements for those aged 71 to 80 have gone from 16.9% to 26%. The reason for this change is unclear.

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Figure 11 - Service agreements for dementia by age, 2020 - 2025



Support services

Dementia **Connect**

Dementia connect is the first line of support for people with dementia and their families in Wolverhampton. The service is provided by Alzheimer's Society and is commissioned by City of Wolverhampton Council to provide tier one and tier two support. The service "gives you personalised help and advice face to face, over the phone or in writing. Depending on your needs, we can offer you information and signposting or ongoing support regardless of whether you are worried about your memory, have a diagnosis of dementia or are a carer, family or friend". Dementia connect Wolverhampton is free service which requires self-referral. The local team support a range of events across the city, including "Singing for the brain", dementia cafes and partnership working with statutory organisations.

Over a six-month period from April to September 2025, 286 people in Wolverhampton reached out to the National Dementia Support Line. Of these, 67 received direct support from the Local Dementia Advisors team. There are 1.5 full time equivalent dementia advisors in the team, and so the team are limited in the activities they can support in the city.

"Those attending as carers all agreed that they would like check-in calls from someone who understands dementia and can offer advice, such as an admiral nurse, Carer's Support or Alzheimer's Society, feeling isolated and that there is a lack of support." – involvement team report on meeting at Molineux memories

Older adults therapeutic **service**

Older Adult Therapeutic Service (OATS) is a service provided by Black Country Healthcare Foundation Trust (BCHFT) to provide a range of community-based therapeutic and recovery support to people of any age who have a diagnosis of mild to moderate Dementia. OATS offers a wide range of support both one to one and within groups including post diagnostic information and evidence based therapeutic interventions such as Cognitive Stimulation Therapy and memory strategy skills. OATS practitioners can also signpost and support people to other Dementia support within the community. The short-term support offered by OATS is most beneficial shortly after diagnosis, and referral is predominantly from the BCHFT Memory Assessment Service or community Dementia support services.

Admiral nursing **service**

"Admiral Nurses are a lifeline. Without them, I wouldn't know where to go or what to do."
— Carer who recently lost her father, speaking to ICB involvement team

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Admiral nursing is a clinical support service for patients and families who are having additional challenging needs not able to be met by other dementia services. The service is commissioned by BCHFT and supported by Dementia UK. Admiral nursing receives strongly positive feedback from patients and families. Due to the intensive nature of support provided and limited capacity, the threshold for referral is high. In addition to direct support, Admiral nurses provide training and education for the health and social care workforce. Admiral nurses accept referrals for the following reasons:

- The family/carer are struggling to cope with managing risks & challenging needs, or the presentation of the person with Dementia.
- The family/carer feel unable to cope with caring due to feeling of loss, guilt, stress and/or depression.
- The family/carer are neglecting their own physical/ mental health needs due to their caring role.
- The family/carer need support with psychological interventions to help them adjust and develop skills to support complex needs/behaviours, particularly around periods of transition.
- Conflict has arisen, which is affecting the family/carer ability to meet the person's needs.
- The family/carer require support recognizing/ adjusting/ coping with End of life. The carer needs advice around Advance Care Planning and future planning.

Physical health secondary care admissions

Hospital admissions for acute physical health problems have a particular importance in the disease course of dementia as they can “trigger distress, confusion and delirium... that can contribute to a decline in functioning and a reduced ability to return home to independent living”.(3) Nationally, people with dementia occupy an estimated 25% of acute hospital beds,(11) and stay in hospital twice as long as other patients over 65.(12)

Local data

Data for Wolverhampton residents admitted to New Cross hospital were provided by the Black Country integrated care board for a two year period from April 2023 to April 2025. The data for dementia patients include those with a diagnosis of dementia who are admitted for any reason, not limited to dementia-related admissions. Key findings are presented below, and the full data is provided in [appendix 1](#). Data access and interpretation was limited by capacity issues within Royal Wolverhampton Trust, City of Wolverhampton council, and Black Country ICB. Partners should undertake further work to understand the patterns of admissions and discharges of dementia patients in more depth than has been possible in this JSNA; specific recommendations are outlined following the data below.

Over the period studied, there were an average of 3527 annual admissions of patients diagnosed with dementia. From the data provided, we do not know how many of these were repeat admissions. Dementia patients spent 52% longer in the emergency department (ED) compared to the over-65 general population. Although there is likely to be some confounding from higher rates of comorbidities, this finding shows that dementia patients are systematically different from the population as a whole and need specialised support. Encouragingly, the Royal Wolverhampton Trust are appointing two specialist nurses to support dementia patients throughout inpatient admission.

Out of all admissions of dementia patients, 33% of were short stay admissions of less than 24 hours. It is difficult to find comparable statistics for the general population, but around a third of patients nationally are admitted and discharged on the same day.(13) Dementia patients aged over 65 had a median length of stay of one day longer than general admissions aged over 65.

The data showed that of all admissions for dementia patients, 30% were diagnosed with Alzheimer’s disease and 16% with vascular dementia. 53% were diagnosed with “unspecified dementia”, which limits the strength of our interpretation but may reflect inaccurate coding of mixed dementia.

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Out of admissions of Wolverhampton residents with a dementia diagnosis, 59% of episodes ended in discharge to the patients' own residence. We do not have the data to compare to the rate in the general population.

Table 2 - Annual average rates of selected indicators, New Cross admissions data 2023 to 2025

Indicator	Number	Proportion of dementia admissions
Hospital admissions in patients with dementia 65+	3527	baseline
Dementia admissions 65+ that are short stays	1155	33%
Hospital admissions by dementia sub-type		
Vascular dementia inpatient admissions 65+	555	16%
Alzheimer's dementia inpatient admissions 65+	1073	30%
Unspecified dementia inpatient admissions 65+	1868	53%
Discharge		
Numbers discharged to own residence, dementia inpatient admissions 65+, compared to total number of dementia admissions	2093	59%

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Table 3 - Average time in the emergency department (ED)

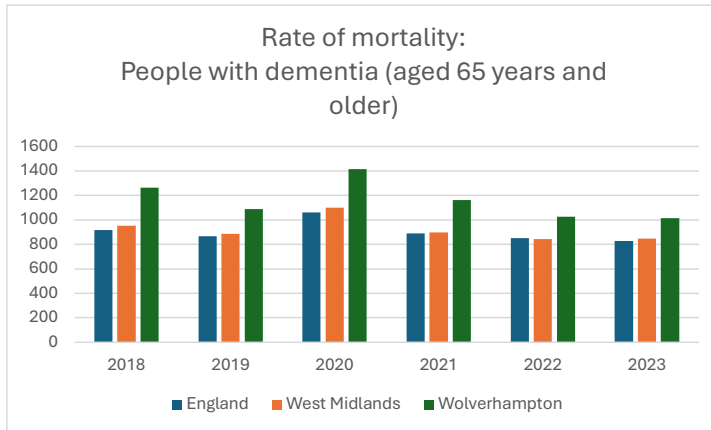
Patient group	Minutes in ED	Comparison
All patients 65+ (minutes)	426	baseline
Dementia patients 65+ (minutes)	648	152%

Recommendations for future work

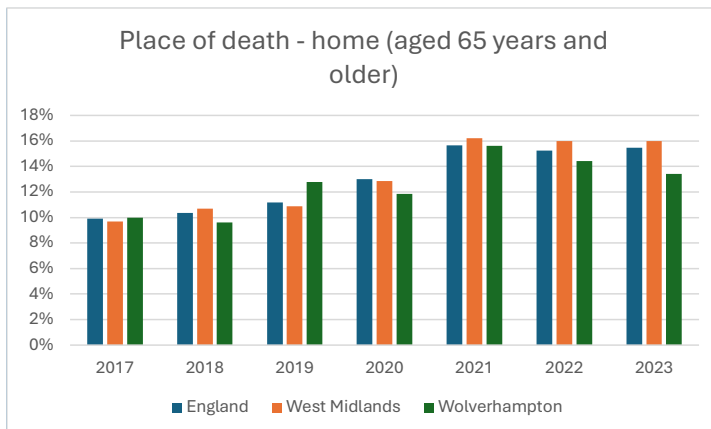
As outlined above, understanding acute admissions is fundamental to understanding the needs of people with dementia and their carers. Due to data access issues, this JSNA has not been able to establish a firm evidence base for future action. Further work is recommended to address the questions below based on discussions with partners and findings from the National Audit of Dementia.(11)

- What conditions do dementia patients commonly present to hospital with?
- What are the characteristics of admitted patients?
- What is the rate of adverse events for dementia patients compared to the hospital population?
- How effectively is pain assessed for inpatients with dementia?
- What proportion of patients have a personal information document at the bedside?
- What are the common barriers to discharge of dementia patients?
- How high are readmission rates, and what is causing readmissions?
- What proportion of staff have completed dementia specific training, and to what level?

Mortality and place of death

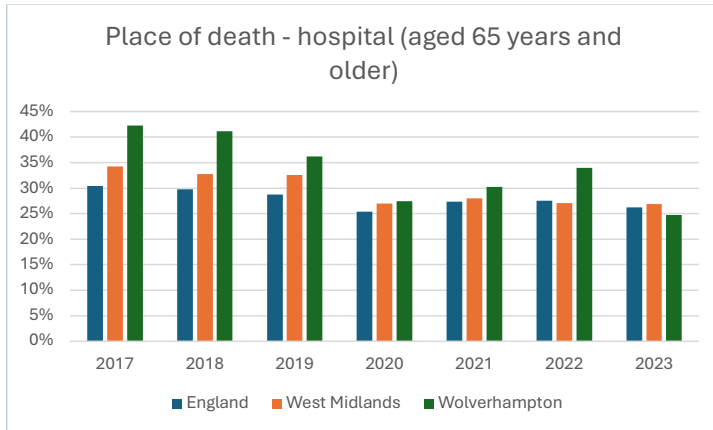


These data show the mortality rate for individuals with dementia or Alzheimer's disease cited on the death certificate, and are expressed per 100,000 population aged 65 and over. Wolverhampton's rates are higher than national figures, which may be influenced by higher diagnosis rates. Data are taken from the Office for Health Improvement and Disparities' fingertips database.



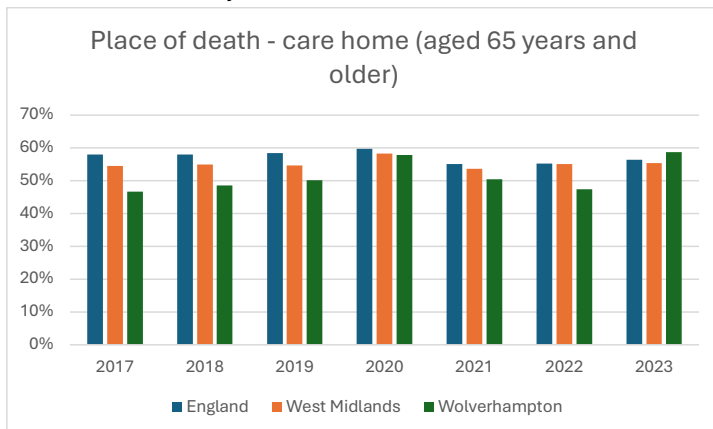
Rates of deaths at home among all older adults are below the national and regional average. Rates specific to patients with dementia are not available locally for this indicator and for those below. A high proportion of dementia patients report a preference to die in their usual place of residence, and so this is an important indicator of quality of care and responsiveness to patient demand.

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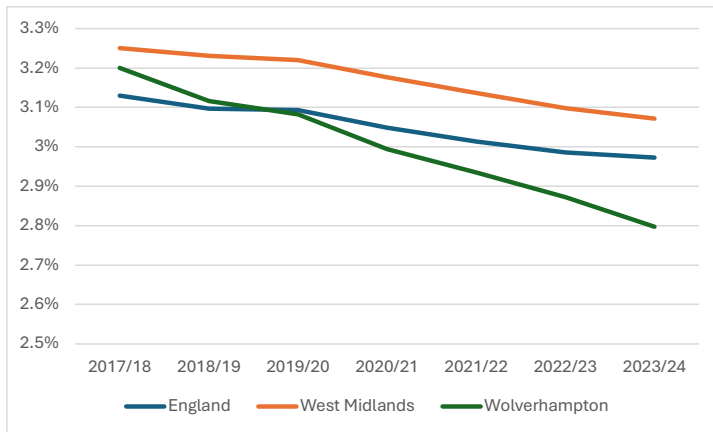
Most patients express a preference not to die in hospital, instead choosing familiar, supportive environments. The latest data for Wolverhampton sit below the national and regional figures, a reduction from previous years. This may be linked to ongoing work to promote care in the community.



Wolverhampton consistently shows a lower percentage of deaths in care homes for older adults compared to England and the West Midlands from 2017 to 2022, and a higher percentage in 2023. Care homes often provide specialised dementia support, and low rates of deaths in care homes may indicate gaps in service provision.

Risk Factors

Figure 12 - Coronary heart disease prevalence

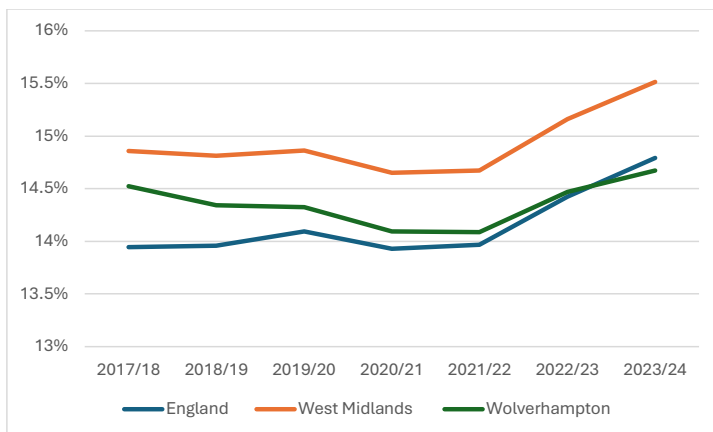


The data for the Risk Factors section are taken from primary care Quality and Outcome Framework (QOF) disease registers, accessed via from the Office for Health Improvement and Disparities' fingertips website. Coronary heart disease (CHD) is a known risk factor for dementia due to its relationship with vascular dementia and cognitive function. Rates in Wolverhampton have experienced a steady decline, indicating significant local progress (mirroring national progress) in preventing CHD. Overall rates of CHD in Wolverhampton are lower than the national and regional averages.

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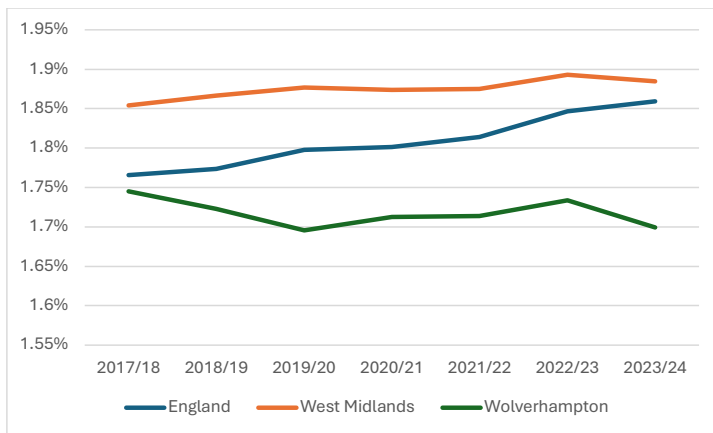
Figure 13 - Hypertension prevalence



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Hypertension is a key risk factor for dementia, as it can damage blood vessels in the brain and impair cognitive function. Wolverhampton's number of patients with established hypertension, has remained relatively stable, recovering since a drop during the Covid pandemic. Latest diagnosis rates sit below the national and regional average.

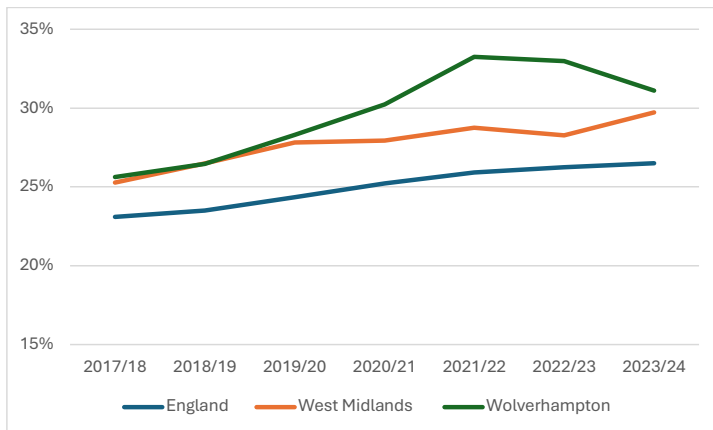
Figure 14 - Stroke prevalence



Wolverhampton consistently reports lower stroke prevalence than both England and the West Midlands throughout the period studied. This difference has increased over time. This contrasts with the higher rate of vascular dementia as a proportion of all dementia cases in Wolverhampton. This finding is unexpected and not fully understood, but may be in part due to lower average age in Wolverhampton.

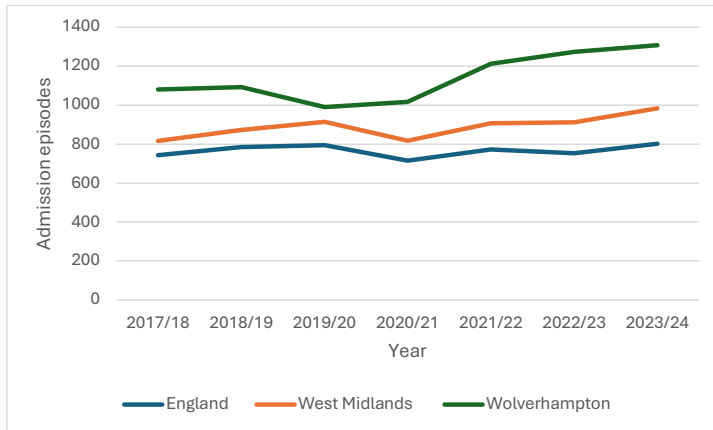
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Figure 15 - Adult obesity prevalence



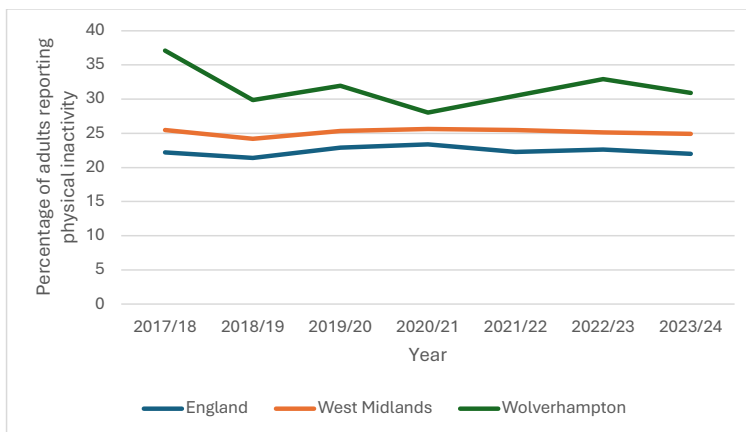
The data displays that Wolverhampton consistently records higher adult obesity rates than both England and the West Midlands, with a particular increase post-covid. Of note, there has been a recent decrease in obesity prevalence in 2023/24.

Figure 16 - Admission episodes for alcohol-related conditions (40 to 64 years)



Hospital admissions linked to alcohol for residents aged 40 to 64 years old are consistently more frequent in Wolverhampton than in England or the West Midlands, indicating a greater local burden of chronic alcohol misuse. This is an important modifiable risk factor for dementia and alcohol-related brain damage.

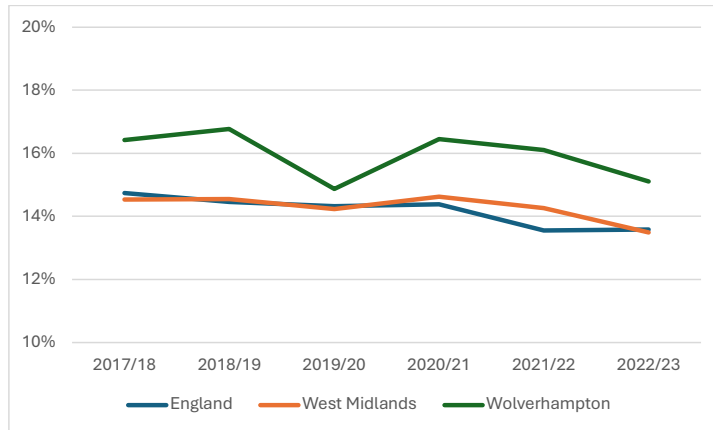
Figure 17 - Percentage of adults who are physically inactive



Source: Fingertips PHE

Wolverhampton consistently shows higher rates of physical inactivity than England and the West Midlands.

Figure 18 - Adult smoking prevalence



Wolverhampton's adult smoking rates are consistently above the national and regional average.

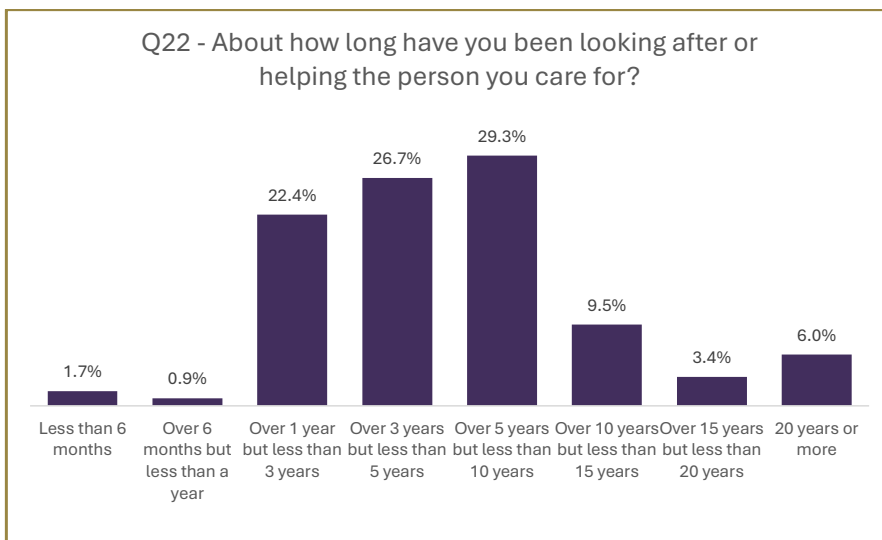
Unpaid carers

The economic value of unpaid care in the UK is estimated at £184 billion a year, roughly equivalent to Government spending on the NHS.(14) Patients require more care and support as the disease progresses, with the costs associated with care in severe dementia estimated at £80,500 per person per year.(4) However, despite the scale of their contribution, carers often report feeling unsupported by statutory organisations and suffer negative effects on their own health and wellbeing. The following insights are from carers in Wolverhampton who responded to the NHS England Survey of Adult Carers in England 2023/24. Respondents are only included if they care for a person who has dementia. This is the latest available data at the time of writing, but findings from the latest national survey of adult carers will become available in spring 2026. The implementation group will review these findings on release and update action plans accordingly.

Who are unpaid carers?

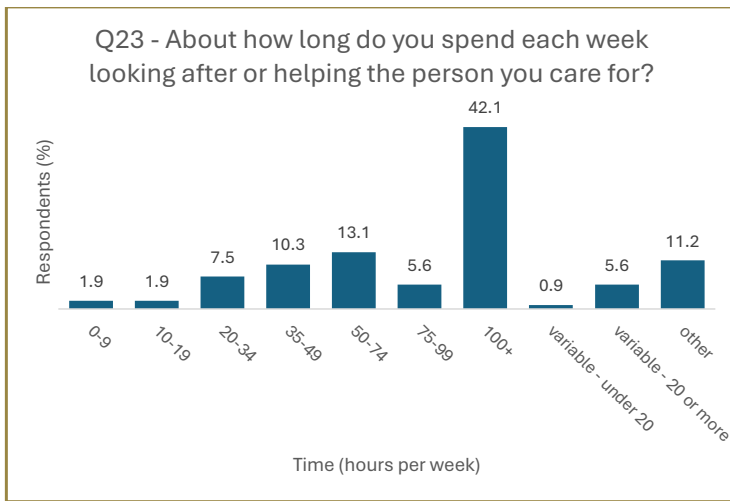
83% of carers stated that they live with the person they are caring for. Carers who responded to the survey tended to be in longer term caring roles (Figure 19). Most carers are retired (62% of respondents), with 12% in part-time work and 3.5% in full time work. A significant proportion (21%) report that they are not working due to their caring responsibilities. An estimated 70% of care hours are provided by women.(15)

Figure 19



Activities of unpaid carers

The Carers survey shows that unpaid carers spend an extremely high number weekly hours on caring activities, with 42% reporting spending over 100 hours a week. This is a highly significant contribution to dementia care in the city which often goes unacknowledged. This time spent caring means that many carers feel they do not have enough time for themselves (71% of respondents), while 19% report not having any time for themselves at all.

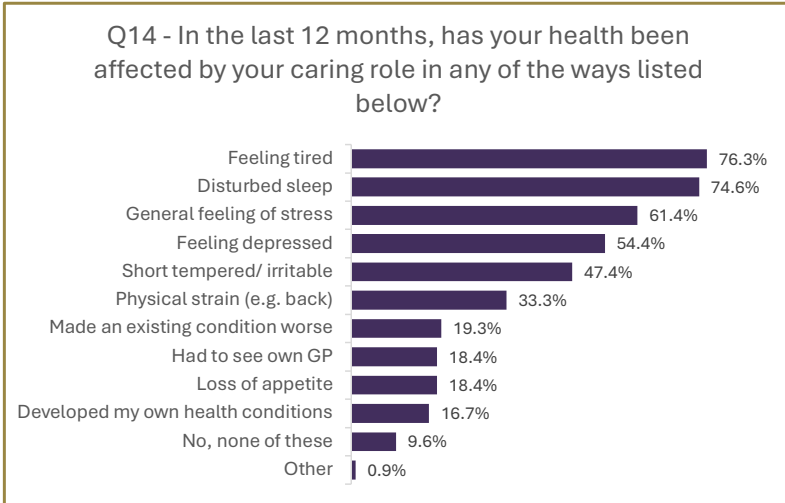


Impact on carer's health

“[caring is] taking its toll on carers, we need to do more to look after them”. – D, speaking at Adult Voices for Choices

Due to the demands placed on them, carers have poorer health outcomes than the general population for both physical and mental health (ref carers JSNA). Of people who responded to the survey, 54% said that caring had caused them to feel depressed in the last 12 months. The consequences of caring caused 18% to see their own GP in the last 12 months.

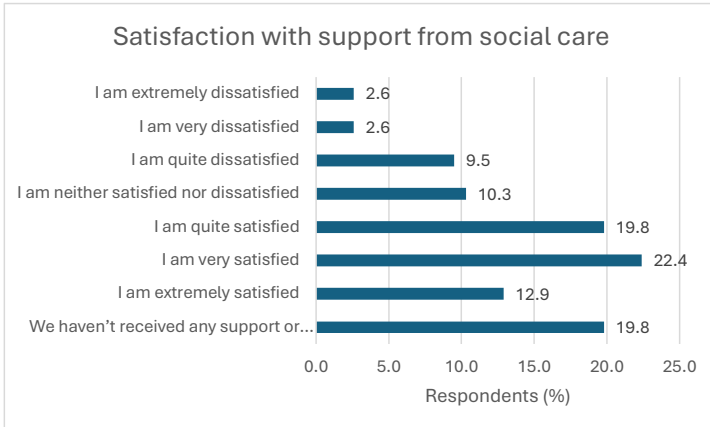
Figure 20



Support

Respondents gave a mixed picture when asked about support received from social services with 55.1% reporting generally positive feedback on support received, against 14.7% stating they were either quite, very or extremely dissatisfied with support provided. Almost 20% stated they had not had any support or services within the last 12 months. It is important to note that the survey is more likely to be answered by carers who are already engaged with social care, and the proportion not receiving support is likely to be higher among non-respondents. As an illustration of this, Carers UK estimate that only 25% of unpaid carers for people with dementia know about carers assessments, and only 8% have received one.

Figure 21



“There is a carer’s group at the Molineux on a Friday, but the members here today find it too much of a challenge to attend as they’d need to arrange respite. None of the group had previously heard of Carer Support or of what options are available for respite.” – ICB involvement team speaking to attendees at Molineux Memories, September 2025.

Services for carers

Available support to all age carers

The Early support team in Wolverhampton has an active relationship with over 7,000 unpaid carers including adult carers, parent carers and young carers. There is strong commitment to identifying carers who remain hidden, with 27,000 people identified as a carer in the 2011 census. Community engagement is ongoing, alongside promotion and advertising of the support offer. The team provide:

- Statutory Care Act 2014 Carer Conversations (assessments) that are strengths based meaning any resulting care and support plan is person-centred and created with better outcomes for the carer at its core. This is annually reviewed and updated. The care and support plan looks at a carer's strengths and what they can do, not what they can't do with available support or sign posting put in place to enable carers to continue in their caring role.
- Emergency card and contingency planning. This is vital to carers knowing a plan has been arranged so if anything happens that prevents them from carrying out their caring role there is someone to look after the person they care for.
- Carers bulletins and regular information updates
- Carers peer support groups, events and activities
- Specialised Carers welfare rights information and advice
- Carer helpline available five days a week on 553409 to answer general enquires or offer support to carers whose caring role may have increased
- Home Based Respite (both one off and sitting service) if identified as an outcome during the carer's conversation. This helps carers to attend appointments and promotes their wellbeing by pursuing social activities, volunteering or carry out practical day to day tasks such as shopping.
- One off Direct Payments are also available if identified as an outcome of the carer's conversation to support carers to have a break or make purchases that help them to maintain their caring role.

Needs and future opportunities

"I'd love to go to the Friday carers group, but I can't leave him alone. There's no respite."
— Carer at Molineux Memories, speaking to the ICB involvement team

There has been a reduction in the availability of respite care (including day respite and emergency respite) across the city, with several facilities unable to reopen after Covid-related closures. Respite care gives carers time to address their own needs, preventing

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carer burnout and prolonging the time that the cared-for person can remain in their home. Increasing the availability of respite care should therefore be a priority for all partners. As well as maximising the autonomy of the cared-for person and the wellbeing of the carer, this has the potential to reduce the costs of long-term care for the authority.

The Royal Wolverhampton Trust is signed up to John's campaign, which enables carers to stay in hospital with people with dementia outside of normal visiting hours. Residents have noted that awareness of this provision is low among carers, so people are not requesting it. They also note that awareness is low among hospital staff, leading to carers being requested to leave even though they are entitled to stay.

“none of the carers I know have ever heard of it, so they don't stay, even though they can, they just don't know” – P, carer for a person with dementia.

The wider needs identified in this JSNA are reflected in the needs of carers, including the need for pre-diagnostic support while waiting for assessment, and access to good quality information on dementia. The Wolverhampton Technology enabled care project is an exciting development to leverage technology to maximise the support that can be provided to carers. Work on a digital information platform is currently in early stages.

An action plan for carers is currently in development within Adult social care. For this plan to fully address the needs of carers of people with dementia, it should address the following issues identified in this JSNA:

- Outreach to carers who have not received a carers assessment
- Availability of respite care
- Training for carers on dementia
- Information provision and signposting. Ongoing work to improve the quality of information available to carers should address dementia specifically.
- Raising awareness of John's campaign

Evidence review

This evidence review seeks to answer the question: “What interventions and working practices are most effective, according to the evidence, at: preventing dementia, providing early and equitable access to diagnosis, and improving clinical outcomes and quality of life for people living with dementia and their carers?”

This evidence review is structured around NHS England’s “Well Pathway for Dementia”.(16) We searched for relevant studies on Pubmed and Google scholar, and reviewed relevant NICE quality standards,(17) guidelines(18) and Department for Health and Social Care (DHSC) guidance. We have further strengthened our review by using the DHSC’s “Dementia 100 pathway assessment tool”.(19) This self-assessment was completed by partners across Wolverhampton in 2023/24. We have focussed our review on criteria scored by local partners as low performing, and priorities identified by patients through the ICB patient insights work.

Preventing well

“How can we embed dementia prevention in Wolverhampton, both through healthcare services we deliver and the wider environment we live in?”

Raising awareness of the risk factors for dementia has been shown to be crucial to reducing dementia rates, given that up to 45% of dementia cases are preventable.(7) Preventable risk factors for dementia include behavioural factors such as smoking, high alcohol consumption and physical inactivity. Commissioned services that are already addressing these risk factors should be proactive in informing residents that a healthy lifestyle can reduce the risk of dementia, for example in NHS health checks, weight management, smoking cessation and drug and alcohol services.(19) Dementia risk can be modified at all ages by factors such as education level, demonstrating the importance of a life course approach to prevention.(7,20)

Dementia risk is substantially affected by the environment that we live in and the impacts of wider society. Evidence has shown that social isolation has strong links to risk of dementia onset, increasing risk by 50% to 60%.(21) Simple interventions, such as increasing social activity and addressing hearing loss, can be effective methods of reducing dementia risk. Similarly, prevention strategies within housing, transport and green spaces can also serve as important protective environment factors that reduce risk of dementia. This JSNA therefore highlights the good work of community organisations in Wolverhampton who are enabling people to continue to be connected to their community, such as the work of Age UK Wolverhampton. ||

Air pollution is linked to an increased risk of dementia, and although the mechanisms of this link are not clear, it adds to the existing evidence base for promoting cleaner air.(22) The city of Wolverhampton Council continues to work with regional partners to maintain

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Commented [KW42]: in the prevention section, aren't we thinking about general social activity rather than dementia specific?

good air quality as outlined in the health protection strategy, with actions including the launch of the WMCA air quality platform.(23)

Preventative strategies also need to consider inequity as dementia risk does not fall equally across society. Factors such as lower levels of education, higher levels of deprivation, and differences in health status across ethnic groups all contribute to unequal risk. Wolverhampton's diverse communities therefore face varying levels of vulnerability to dementia. This highlights the need for targeted approaches that address the wider determinants of health, ensure equitable access to prevention and early intervention services, and tailor community engagement to meet the needs of specific groups.(20)

Diagnosing well

How can we best support our residents to access a dementia diagnosis early and equitably? What is best practice in post diagnostic support from healthcare services?

Being formally diagnosed with dementia enables access to medical treatment and community support, which is why NICE quality standards recommend no more than a six week wait for initial assessment for people with suspected dementia.(17) Most diagnoses of dementia are made by a specialist service, which in Wolverhampton is the Memory Assessment Service (MAS) run by Black Country Healthcare Foundation Trust (BCHFT).

In Wolverhampton, General practitioners (GPs) can contact the Memory Assessment Service for advice by phone or email, but there is no formal advice and guidance process to enable this. This is considered to be best practice in service design, and may facilitate GP diagnoses where appropriate.(19) Tools to enable GP diagnoses of dementia such as the "Diagnosing Advanced Dementia Mandate (DiADeM)" will be essential in achieving this aim.(24)

It is acknowledged in guidance that diagnostic tools and the support provided may be inappropriate for diverse communities.(18) For example, cognitive tests which require knowledge of British history may be less appropriate for individuals born outside the UK.(25) Local diagnostic services have confirmed that alternative tools are in use and that plans are in place to monitor and address equity of access.(19)

Patients should have follow up opportunities to discuss their diagnosis and this should be embedded within the local pathways.(18) This would address concerns raised by patients during ICB insight work that many have felt unprepared for changes in symptoms as the disease progresses.(26) Wolverhampton has a higher rate of completion of annual reviews of care plans than the Black Country average (79% vs 58%) but this still leaves a significant number of patients without an up-to-date care plan review.

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Commented [IH44]: Need GP and MAS input on this one. Is an A&G service needed/feasible?

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In Wolverhampton, Dementia Connect are commissioned to support all patients and families, and Admiral Nurses are commissioned to support those with higher needs. Together with MAS and general practice, follow up care for dementia patients must be coordinated between health and social care organisation .(19) This includes discussions of prognosis and advance decisions.

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NHS and the Royal College of Psychiatry recommend that it is best practice for every dementia patient to be given a community “co-ordinator of care” professional from health or social care.(19) This professional would be a first point of contact for the patient and carers and would be responsible for co-ordinating care. One example of this system is the Dementia Navigator service in Sandwell.(27) Moving towards this type of system may benefit inter-agency communication in Wolverhampton and should be considered by partners, however the additional resource required would need to be justified by anticipated benefits.

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Supporting well in the community

In the Black Country ICB engagement work, patients have identified a need for more support after discharge from MAS.(26) The evidence shows that this support would lead to better clinical outcomes.(28,29) A large systematic review identified positive effects on neuropsychiatric symptoms after a diverse range of interventions, from psychoeducation for caregivers to music therapy, a form of which is provided by Alzheimer’s Society in Wolverhampton.(28) The Lancet commission on Dementia 2020 recommends targeting social isolation to combat cognitive decline as rates of dementia are significantly higher in those who are socially isolated.(7,30)

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A wide range of activities are provided in the city by the voluntary and community sector, but patients often do not know how to access these.(26) In Wolverhampton, healthy aging coordinators and social prescribers perform a signposting role, but there are gaps in coverage across the city. Healthy aging coordinators have identified that the waiting list for services such as occupational health is a barrier to delivering high quality support in the community.(personal communication, G. Evans, September 2025)

Supporting well in hospital

At any one time one in four hospital beds are occupied by people living with dementia.(31) One key recommendation from the Dementia 100 tool is for dementia patients in hospital to have an early review from a dementia specialist clinician,(32) which has been shown to reduce adverse events and improve patient experience. The Royal Wolverhampton Trust are currently recruiting two nurse specialists to review dementia patients. Upskilling all staff in dementia care should improve patient outcomes and is considered best practice,(19) although the current evidence base is weak.(33)

Living well

Unpaid carers undertake the majority of caring for people with dementia, but this can sometimes come at the cost of their own health and needs. An evidence review for the Unpaid Carers JSNA 2022 found caring impacts in a range of domains as outlined below.⁽³⁴⁾ The time demands of caring have a knock on impact on employment and schooling, with young carers aged 16 to 18 having a much greater chance of not being in education, employment or training.⁽³⁴⁾ While providing care can be personally rewarding, a 2020 survey from Carers UK found that 70% of carers experienced negative impact on their physical or mental health as a result of caring.⁽³⁵⁾ Research from 2013 found that 44% of carers had been in debt due to caring, and many carers give up full time employment for their caring duties. Carers UK reported that 80% of carers have felt lonely or socially isolated as a result of their caring role; although the measures are calculated differently and are not directly comparable, this is still higher than the general population rate of 7%.⁽³⁴⁾

A review by Arksey et al. found that respite services promote improved quality of life in both patients and carers, although the quality of evidence was not sufficient to calculate an effect size.⁽³⁶⁾ Respite services are one key way of supporting unpaid carers, a priority identified throughout the engagement with patients, families and professionals in Wolverhampton.⁽²⁶⁾

Alongside respite services there is a need for peer support groups to promote social connection and shared learning. Education and skills training can empower carers with the tools to provide high quality care, but this provision must be tailored to their needs and preferences.⁽¹⁹⁾

Wolverhampton was awarded Dementia Friendly City status in 2018 in recognition of work done by the Dementia Action Alliance and partners. One element of this is dementia inclusive urban design, which emphasises practical infrastructure such as accessible toilets, clear signage, and benching or seating in open spaces.

Dying well

In Wolverhampton, review of advance care plans tends to be opportunistic, for example on hospital admission. Making this more systematic may reduce the stress of hospital admission for patients and families, and prevent unwanted admissions.⁽¹⁹⁾

The NHS England “Well pathway for dementia” highlights the need for patients to be able to die in the place of their choosing. For many dementia patients, this is their usual place of residence, as familiar surroundings and people can help to settle agitation.⁽¹⁹⁾

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The progressive changes in decision making and memory in dementia mean that tailored training for staff is needed to address these unique demands. The Admiral nursing service has taken a leading role in dementia training for healthcare professionals in Wolverhampton, delivering training to over 200 staff as part of Dementia action awareness week. Making this a regular event would improve the end-of-life experience for dementia patients in the community.

Lived experience

“You really don’t know unless you’re living with it.”

Attendee at Molineux Memories, speaking to ICB involvement team

Key priorities for patients

- Information provision
- Post diagnostic support
- Support for carers, particularly in crisis
- Earlier conversations about dying well

Across the Black Country, staff from the ICB have spoken with 16 groups and around 150-200 people living with or caring for someone with dementia to understand their views and experiences. We have directly presented their findings for Wolverhampton and the Black Country below:

Patient priorities overview – Black Country

- **Preventing Well** – The belief that active healthy people won't get dementia
- **Diagnosing Well** – received support through diagnosis at memory clinic, but once diagnosed given too much information to digest and left unsupported, unsure what to do next.
- **Supporting Well** – Most support comes from carers, who themselves feel unsupported and forgotten, with no time for themselves or respite, impacting their own wellbeing. Other support comes from dementia cafes and groups who might not be trained or know where to signpost.
- **Living Well** – More support is needed for carers, particularly when they are in crisis and have no-one to contact.
- **Dying Well** – There is not enough information or support in planning end of life care, Power of Attorney or encouraging conversations around dying, these need to be early on, often go ignored until the later stages of dementia, when it may be too late.

Patient priorities – Wolverhampton

The gap in provision after diagnosis stood out the most in Wolverhampton, as well as the 'bundle' of information which people said they would never read.

- **Preventing Well** – Not enough is known about dementia by young people, there is a need for educating young people to live healthily and be aware of the signs. We heard that many young people are scared of those who have dementia.

“Find out what causes it, such as isolation and get the message out there.” – attendee at Adult voices for choices, September 2025

- **Diagnosing Well** – People have to fight for a diagnosis, are often told it is nothing, GPs need to listen more to carers, once referred to the memory clinic there was consistent praise.
- **Supporting Well** – After being discharged from the memory clinic they are not seen again and don't know what to do, some have said it has been years. All spoke of gap / lack of support, some mentioned teams being short staffed and phones unanswered. There was much praise for Admiral nurses, though a need for more and sooner.

“after diagnosis there isn't a team who continue this support.” Attendee at Alz Café, Penn, September 2025

- **Living Well** – Carers need support and more respite to stay well enough to continue caring. Support groups like dementia cafés are a great comfort and help people to live well. We heard people want medical professionals to "talk to me and not my carer".
- **Dying Well** – Most said they don't have plans and don't like to discuss dying, we heard this is a cultural thing particularly in Caribbean families. Some spoke of having a Power of Attorney. We heard how guilty carers feel when loved ones go into care.

“In our culture, you don't admit to mental health issues—especially dementia. People think it's just for white people.” — Asian British man at Bantock Park, September 2025

Further insights

To inform the 2025 dementia strategy refresh, the Black Country ICB involvement team spoke to a further 73 people across Wolverhampton in 2025. This included discussions with people at:

- Adult Voice for Choice Forum
- Bantock Park Memory Café (Alzheimer's UK)
- Cranstoun
- LGBT Sparkle Dementia Carer
- Lived experience consultant
- Molineux Memories (Wolves Foundation)
- Refugee and Migrant Centre (RMC)
- Tackling Dementia Support Group (Wolves Foundation)
- Wolverhampton Healthwatch

These discussions highlighted some additional themes complementing previous work in this area. Residents reported that not all professionals know where to signpost for support in the community. The dementia services directory appears to be widely provided, but people still report a lack of support and a lack of clarity on what comes next. People with low literacy or digital skills reported struggling to access services.

Some carers do not feel well supported within the system, although the services that do provide support are highly praised. There is a lack of availability of respite care, which prevents carers from attending carers' groups. Some felt that staff within key services had a poor understanding of dementia, leading to unnecessary difficulties in e.g. applying for a blue badge.

Participants reported that communication between services can be fragmented, with different advice provided from each.

Cultural stigma and mistrust of services were identified as major barriers to early diagnosis and support in some migrant, African, Caribbean, and Eastern European communities.

The outcomes from these conversations with 73 Wolverhampton residents have been summarised in the following recommendations, taken from the ICB involvement report:

- Co-producing a citywide dementia directory and signposting resource
- Mapping and promoting free financial advice
- Introducing joint dementia awareness training for NHS and Council staff
- Exploring a carer recognition scheme and ambassador network
- Raising financial inequity issues for dementia at regional forums

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- Piloting culturally sensitive dementia outreach with community and voluntary sector
- Developing a young carers dementia toolkit in partnership with schools
- Strengthening partnerships with Wolves Foundation and other community anchors
- Promoting digital literacy and non-digital alternatives for service access

Expert review: Dr Karan Juttla

The ICB patient insights findings were reviewed with Dr Karan Juttla, Head of the Centre for Applied & Inclusive Health Research & Dementia Lead at the University of Wolverhampton. We discussed with her how these findings compare to her research on the patient experience of dementia in underrepresented communities in Wolverhampton.

Across Wolverhampton and particularly in ethnic minority groups, people tend to rely on their “infrastructure of support” that they had prior to diagnosis, i.e. their community. As an example, Dr Juttla’s research in Wolverhampton has identified 25 distinct communities of up to 40 people each, involved in peer support.

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Dementia onset is often seen as random, but if a cause is considered it may be seen as stress related or an inevitable part of aging. It is relatively unusual for people to have a strong belief that healthy people do not get dementia.

There are concerns raised in the literature that dementia diagnosis may be less accurate in minority ethnic groups because assessment tools are not culturally appropriate. Currently, some people have reported that the availability of appropriate assessment varies depending on the practitioner. The JSNA evidence review did not identify a clearly superior diagnostic tool to those already in use by MAS.

After seeking help from within their own community, patients will seek help from their GP. Cultural barriers usually do not stop people from consulting, so GPs are a key conduit for information provision and signposting.

Newly diagnosed patients often want to keep going with their normal lives – rather than accessing specific support such as dementia cafes. This reinforces the importance of adapting communities to the needs of people with dementia so that they can continue to fully engage in their communities. Post-diagnostic support should be culturally appropriate. It is not always clear to patients and families what services they will have to pay for, and what will be free. This can be an obstacle in attendance.

Families have identified expectations from healthcare professionals that family members will translate, but people often struggle with specific medical terms. Discussed that this is an ongoing issue.

There is strong alignment between Dr Juttla’s work and the ICB insights work, including the following points: Patients are often not warned about what to expect and how the condition will change over time. Carers support out of hours and respite care provision is a priority in all communities. The difficulties talking about death identified in Black ethnic groups are also reflected in the south Asian community.

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Overall, the findings of the Black Country ICB patient insights work are in broadly alignment with the views of residents involved in Dr Juttla's research. This alignment was anticipated as the ICB work was done with a diverse group of patients. However there are additional patient priorities outlined above that are important not to overlook, for example around how to tailor support in a culturally appropriate way.

Survey of professionals

Introduction

A survey entitled 'How can dementia care be improved across Wolverhampton?' was sent out to professionals across the city from a range of sources, with the survey running from August to October. The survey responses have been summarised below to cover six key areas: respondents, referral routes, underserved groups, interagency coordination, information provision, and unmet needs. Where appropriate, Braun and Clarke's (2006) thematic content analysis approach has been employed. This involves reviewing the responses to identify codes, which are then grouped into themes as part of an iterative process. Thematic analysis was performed by Charlotte Duckett and reviewed by Isaac Hosier.

Respondents

Out of the 21 respondents to the survey, the majority (16) were from health care organisations. These respondents represented primary and secondary care in both physical and mental health provider organisations. Three respondents were from social care, and two were from the voluntary and community sector (VCS). Respondents were engaged in a wide variety of roles in relation to dementia including clinical management, care act assessments and facilitating peer support in dementia cafes.

Referral Routes

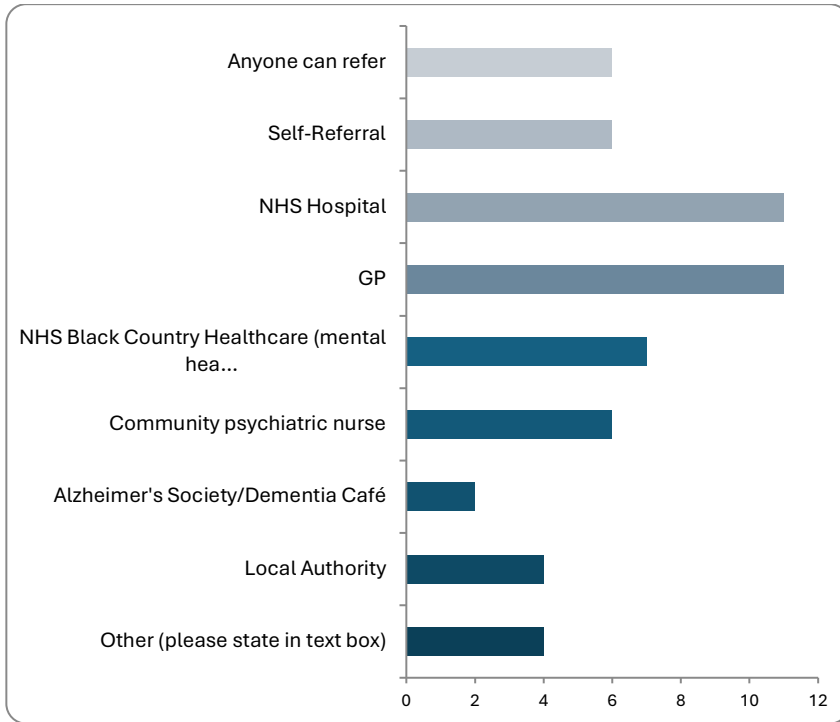


Figure 22 - What are the referral routes into your service?

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Respondents to the survey received referrals from a range of sources, including statutory services and open referrals. Of note, a low number of respondents reported receiving referrals for support from Alzheimer’s Society/Dementia Café (2) and local authority (4). This may be due to the low numbers of non-healthcare respondents to the survey, but may indicate a need to increase collaboration between VCS, local authority and healthcare organisations.

In answer to the question: “Where do you refer your clients if they need additional support?” the most common responses were Alzheimer’s Society/Dementia Café (17) and local authority (16), followed by NHS Black Country Healthcare (13) and GP (12), showing good usage of formal services. Social prescribing and the community carers support team were mentioned once only, and Memory Matters was not mentioned, indicating an underuse of some sources of support. Admiral nurses were mentioned less often, possibly because of the higher needs requirements to access their services.

Underserved Groups

Respondents were asked three questions related to underserved groups, covering any groups of people that require extra support, and any groups that have difficulty

accessing services. The responses to these questions have been analysed using thematic content analysis (Braun and Clarke, 2006). Four themes were identified which highlight underserved groups:

- **People with Young Onset Dementia**
 - o Several respondents identified that there are, “little resources for [individuals with] young onset dementia”. Existing resources and services are not always appropriate because “their needs are often different to those who are older”.
- **People from Ethnic Minority Groups and those whose First Language is not English**
 - o Respondents specifically highlighted that, “there is an unmet need in relation to Black and Asian communities in Wolverhampton”. They also noted that, “there are sometimes barriers with people from different cultures and where English is not their first language”. Issues were also raised about there being a “lack of tailored services to meet individual needs especially with reference to diverse communities”, and the need for interventions to be “culturally and linguistically appropriate”.
- **People Without Access to Transport**
 - o Challenges were also identified for individuals with dementia who do not have access to transport to access services. Respondents noted that issues regarding transport are the “main difficulty for most of our patients”, and there are issues with, “transport costs if they don’t drive anymore”. Whilst public transport works for some, the issue was highlighted of, “older people who live alone and do not drive and have mobility issues with public transport”.
- **Carers and Families of People with Dementia**
 - o Respondents also identified a gap in, “carer support” and support for the families of those living with dementia. Several respondents emphasised the “financial burden for those with dementia and their carers”, causing barriers accessing “costly day services”. It also includes the “lack of information for patients and carers” and a lack of “social support”. Family/carers could benefit from, “training...to manage the situation after diagnosis”. One respondent noted that a direct payment model of social care provision might give more control to people with dementia and their families.

Interagency Coordination

Respondents were asked if they had experienced any problems in delivering their services due to communication issues with other organisations. They were asked to give specific examples, which have been grouped according to the resulting problems:

Inter-agency information sharing

- **Inputting information on referral forms:** examples were given of when referrals have been made without inputting all the relevant information.
- **Accessing notes:** the issue was raised of healthcare services being unable to access notes from other organisations. This means that professionals in different organisations may not know if they are working towards the same objectives.
- **Carers having a lack of knowledge about the patient:** an example was given of when carers support patients at their consultations but do not know much about the patient, so cannot provide the information and support required.

Delays in patients accessing services

- **Delayed or absent responses to referrals made:** examples were given for both health and social care services – this leaves patient waiting to access the care they need, and the referrer must spend time chasing up the referral. Long waiting lists for diagnosis and for occupational health support have been reported. Professionals reported that extended waits for care in the community are delaying hospital discharge.

Challenges in communicating within services

- **Lack of multi-disciplinary team (MDT) meetings in some GP practices:** the issue was raised that the lack of MDT meetings removes an opportunity for professionals to discuss cases (particularly challenging cases) with each other.

Information provision

Respondents were asked whether there were any areas that information given to dementia patients or their families could be improved. Similarly to Section 4, the responses have been analysed according to Braun and Clarke's (2006) thematic content analysis approach, and the themes are displayed below:

- **Delivering Information at the right time**
 - o A key issue raised was the timeframe within which patients are given information – consideration should be given as to when it is appropriate to pass on information to patients and their families. One respondent noted that “people are either given very little information on diagnosis or so much information they don't know where to start”. Given the vast amount of information that is available, it was suggested that services should give

families information in smaller chunks, according to “where they are at with the acceptance of the diagnosis and their needs”.

- **Delivering Information in the Appropriate Language**
 - o Respondents highlighted the importance of the availability of “written information in different languages”. It is not only the patient, but also “the carer may need the information in English or another language”.
- **Delivering Information in an Appropriate Format**
 - o Alongside delivering information in the appropriate language, consideration also needs to be given to the format in which information is delivered – for instance, “bitesize videos” were suggested as an alternative to written information. This contributes to taking a “person-centred” approach to care – looking at what format works best for the patient, according to their communication needs.
- **Topics of Information Delivered**
 - o Respondents highlighted the wide range of topics that patients and their families might require information on. This includes: “financial, social care, emotional and practical advice and support” – as well as information on evening transport and how to access local services. There was a note of poor understanding among the population on the role of medication in treatment (i.e., that it cannot cure the disease). One respondent highlighted that it would be useful to have a “one stop shop” where all this information can be accessed.
- **Amount of information given**
 - o Repeatedly respondents reported that “families are given packs of written information...which they find overwhelming”. It appears that some patients and carers are struggling to access information from the directory of services provided. The layout of the directory may need to be adjusted to accommodate those patients who need information in a simpler form.

Unmet needs

Respondents were asked to describe any key unmet needs or issues for the adults diagnosed with Dementia they work with. To reduce duplication, any needs identified in this section which have been covered in previous sections have been incorporated into those sections and not repeated.

The overwhelming majority of reported unmet need is for social support for people with dementia and their families. Professionals reported a lack of provision, and a lack of awareness of services among their patients. Several respondents reported a lack of culturally appropriate social support, although DOSTIA CIC was highlighted as an example of good practice in this area. Access to support is limited until a diagnosis has been made. Examples of services referenced include day services, respite care and carer's cafes.

Professionals identified another area of unmet need around education and training for people with dementia and their families and for clinical staff. Several professionals commented that "training for family/carers to manage the situation after diagnosis" was insufficient, with "families left to find their own way". Some commented that educational programmes might address the gaps in understanding of dementia they see in the community, with others noting that tier 3 dementia training should be a requirement for all health and social care staff.

Conclusions

While we acknowledge that we would have liked more responses from social care and VCS, we think that this survey still provides useful insight into the views of professionals in the city. The referrals data shows that although services are working together, certain services may be underused. Respondents highlighted large gaps in provision for specific groups, most clearly for those with young onset dementia. Information sharing between organisations is an ongoing concern, making it difficult for treatment goals of services to be aligned. Many professionals identified that residents do not know where to seek support, showing that the dementia services directory may need to be shared more widely and made more accessible. Respondents identified that carers and families need more support in the form of training and social support.

Reference

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Conclusion

This JSNA provides a comprehensive, system-wide understanding of dementia in Wolverhampton and sets out the evidence base required for coordinated action across the city. While it offers a high-level overview, it also identifies specific areas where targeted, practical improvements would have a meaningful impact on residents' lives. It has informed the Wolverhampton Integrated Dementia Strategy 2025–29 action plan and performance measures, through which these findings will be taken forward.

This works shows an opportunity for prevention, with high local prevalence of modifiable risk factors and disproportionately high rates of vascular and mixed dementia. Once dementia is suspected, diagnostic and community services deliver good quality care, but long waiting lists and variable uptake mean that many residents do not receive timely support. Residents and carers often struggle to navigate the pathway, in part due to inconsistent and unclear information across organisations. Support is frequently reactive rather than proactive, reducing opportunities to prevent avoidable deterioration and increasing the likelihood of crisis presentations that place pressure on families and services alike. Despite these gaps in provision and accessibility, there are many instances of exemplary support being provided in the city.

These challenges are not experienced equally. People with young onset dementia, residents from ethnic minority communities, and those facing financial insecurity encounter distinct and sometimes compounding barriers that affect how and when they access support. Addressing these structural inequalities is essential to improving outcomes for all residents.

Overall, these findings highlight the need for sustained, collaborative action to strengthen prevention, improve the accessibility and coordination of support, and ensure that dementia care in Wolverhampton is equitable, proactive and responsive to the needs of its residents.

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Author: Isaac Hosier, Public Health Registrar

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Name	Organisation
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Jon Crockett	Dementia Action Alliance
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Manju Railly	City of Wolverhampton Council, Adult Social Care
Vicki Baker	City of Wolverhampton Council, Adult Social Care
Stephanie Worrall	NHS Black Country ICB
Lee Allen	Alzheimer’s Society
Lindsey Cowan	City of Wolverhampton Council, Adult Social Care
Sobaj Kang	City of Wolverhampton Council, Adult Social Care
Alison Harris	City of Wolverhampton Council, Adult Social Care
Parpinder Singh	City of Wolverhampton Council, Public Health
Alexandra Davy	City of Wolverhampton Council, Public Health
Karan Jutla	University of Wolverhampton
Stacey Harrison	Black Country Healthcare NHS Foundation Trust

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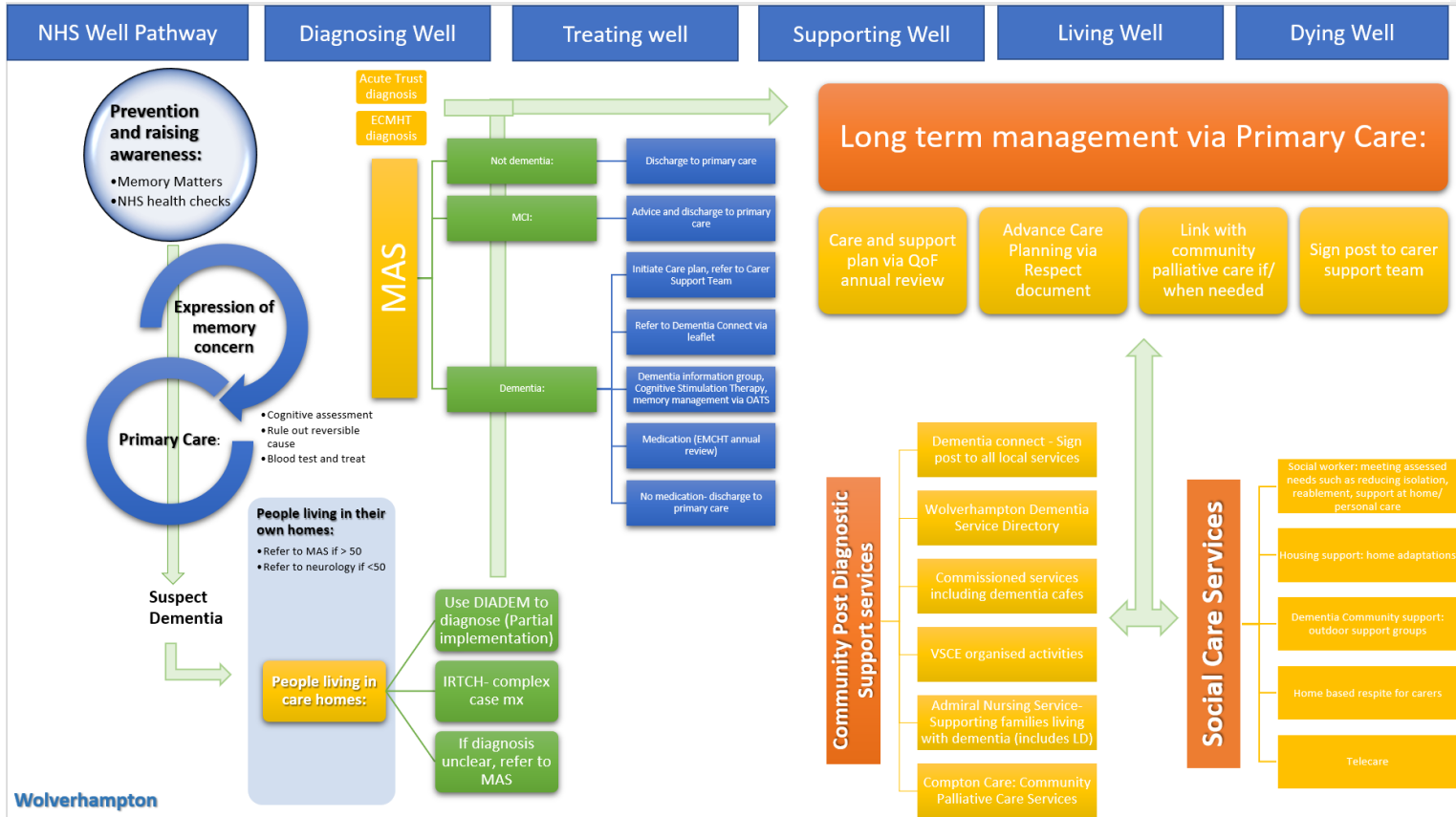
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Appendix 1

Data provided by Black Country ICB on admissions to New Cross hospital.

Registered Populations	2324	2425	2526
Hospital admissions in patients with dementia 65+ (primary and secondary diagnosis) (includes SDEC)	3509	3545	938
Dementia short stay emergency admissions 65+	1223	1087	305
Vascular dementia inpatient admissions 65+	591	518	132
Alzheimer's dementia inpatient admissions 65+	1069	1076	320
Unspecified dementia inpatient admissions 65+	1815	1920	475
Length of stay, dementia inpatient admissions 65+ (median, IQR) = median	5	6	5
Length of stay, dementia inpatient admissions 65+ (median, IQR) =IQR	12	11	11
Length of stay, dementia inpatient admissions 65+ (median, IQR) (compare to hospital median) = median	1	1	1
Length of stay, dementia inpatient admissions 65+ (median, IQR) (compare to hospital median) =IQR	7	8	8
Numbers discharged to own residence, dementia inpatient admissions 65+,	2017	2169	578
Number discharged to own residence, compare to hospital proportion 65+	210115	229240	61728
Proportion discharged to own residence, dementia inpatient admissions 65+, (compare to hospital proportion 65+)	1%	1%	1%
AVG Time in ED, dementia patients 65, in total minutes and then in Hours and Minutes	592 minutes, 9 Hours and 52 Minutes	703, 11 hours and 43 Minutes	687, 11 hours and 27 Minutes
Avg Time in ED,patients 65+	419, 6 Hours and 59 Minutes	432, 7 Hours and 12 Minutes	343, 5 Hours and 43 Minutes
AVG Time in ED, dementia patients 65+ (compare to hospital proportion 65+) if data is robust	0.3%	0.3%	0.3%
AVG Time in ED, dementia patients 65+ (compare to hospital proportion 65+) if data is robust	02:53:00	04:31:00	05:44:00

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Wolverhampton

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