Dementia Health Needs Assessment

George Roberts

Public Health Registrar

Public Health shared service covering Bedford Borough, Central Bedfordshire and Milton Keynes

16th April 2025

Contents

Abbreviations and acronyms

AD	Alzheimer’s Disease
AGEM CSU	Arden and Greater East Midlands Commissioning Support Unit
BBC	Bedford Borough Council
BLMK	Bedfordshire, Luton and Milton Keynes
CBC	Central Bedfordshire Council
CCG	Clinical Commissioning Group
CI	Confidence Interval
OPCMHT	Older People’s Community Mental Health Team
DiADeM	Diagnosing Advanced Dementia Mandate
DISS	Dementia Intensive Support Service
DPH	Director of Public Health
ELFT	East London NHS Foundation Trust
GP	General Practitioner
HCP	Health Care Professional
HNA	Health Needs Assessment
ICB	Integrated Care Board
ICS	Integrated Care System
LBD	Lewy Body Dementia
LDL	Low Density Lipoprotein
MAS	Memory Assessment Service
MCI	Mild Cognitive Impairment
NEET	Not in Education, Employment or Training
NHS	National Health Service
NHSFT	NHS Foundation Trust
NICE	National Institute for Health and Care Excellence
ONS	Office for National Statistics
PLWD	People Living With Dementia
POPPI	Projecting Older People Population Information
QOF	Quality and Outcomes Framework
TBI	Traumatic Brain Injury
YOD	Young-Onset Dementia

Executive summary

Aims

- This Health Needs Assessment (HNA) uses a systematic approach to identify the unmet health and healthcare needs of people living with dementia in Bedford Borough.
- The report also acts as an update to the previously published HNA from 2016.
- The importance of dementia has been recognised by successive governments. It presents a unique set of challenges for the ageing UK population and costs, estimated at £42 billion in 2024, are projected to more than double by 2040.

Findings

- Acting on 14 modifiable risk factors may reduce dementia cases by as much as 45%. Many of these are existing priorities for prevention, such as cardiovascular risk factors including cholesterol, physical activity, smoking and obesity.
- Screening for dementia is not presently recommended, as dementia cannot be reliably detected before symptoms develop. If this was possible, there are no current treatment options which can reverse the course of disease.
- There were approximately 1500 people registered as living with dementia in Bedford Borough in 2024. However, it is estimated that over 3 in 10 people are undiagnosed, meaning there may be almost 2500 people truly living with dementia.
- Dementia is the leading underlying cause of death in England and Wales. The rate of death from dementia is not significantly different in Bedford Borough when compared to the England average.
- The number of people living with dementia in Bedford Borough is estimated to increase between 54% to 86% between 2023 and 2043, depending on the exact model used. This is equivalent to approximately 1500 additional people living with dementia.
- People living with dementia will interact with numerous services across Bedford Borough. This includes those delivered by NHS providers but also various partners in the public, private and voluntary, community and social enterprise sector.
- In depth, semi-structured interviews were held with stakeholders who operated across the dementia pathway. Key themes emerging from these interviews included the acknowledgment of the need for a timely diagnosis, whether all partners were working effectively together the importance of accessibility.
- Focus groups were held with people living with dementia and their carers. People spoke of their difficulties navigating the support available, a desire for holistic care and the importance of attending to carers' needs.

Recommendations

The findings of this HNA have fed into the following recommendations, which are made with consideration of the resources available in Bedford Borough:

1. Ensure people living with dementia and their carers have access to a single point of contact who can help to coordinate their care
2. Make dementia services accessible for all
3. Meaningful collaboration between dementia services to improve outcomes and experiences
4. Engage in primary prevention, reducing risk factors for dementia and other conditions

Section 1 Introduction

What is dementia?

Dementia is an umbrella term describing a syndrome characterised by a decline in cognition to a degree where activities of daily living are impaired (1,2). The word is derived from the Latin root *demens*, which translates as madness or without mind (3–5). This reflects some of the historic stigma attached to the condition, which persists in many cultures today, particularly those where the language spoken has no direct translation for dementia (6–10). Dementia is considered as young-onset (YOD) if it develops before the age of 65 (1,2).

The majority of dementia cases are degenerative or vascular in nature, with the most common subtype being Alzheimer's disease (AD) (11). Other causes include infections, inflammatory diseases, neoplasm, toxic insults, metabolic disorders and trauma. Estimates of the number of people living with each subtype of dementia in Bedford Borough are displayed in Table 1. Dementia is often viewed as chronic, although an estimated 11-14% of dementias are caused by potentially reversible conditions (12,13). There is also an increasing body of evidence on the risk factors for dementia, with recent projections suggesting 14 modifiable risk factors may account for 45% of worldwide dementias, which could thus theoretically be prevented or delayed (14).

*Table 1 Estimated number of people in Bedford Borough living with different dementia subtypes. *Estimated number of people will sum to more than total due to rounding up to represent a whole person. Source: Alzheimer's Research UK Dementia Statistics Hub/ Projecting Older People Population Information.*

Dementia type	**Percentage of all dementias** (15,16)	**Characteristics** (15,16)	**Estimated number of people in Bedford Borough with each subtype in 2023** (17)*
Alzheimer’s disease	60%	Most common and well-known disease causing dementia. Characterised by amyloid plaques and neurofibrillary tangles in the brain, resulting in brain cell death.	1454
Vascular dementia	15%	Caused by reduced blood supply to the brain, often as a result of a stroke and can have a more acute presentation.	364
Mixed dementia	10%	Characterised by the presence of more than one type of dementia.	243
Dementia with Lewy Bodies	10%	Named for the build-up of abnormal proteins in the brain called Lewy bodies. Symptoms can include hallucinations and sleep disturbances. Dementia precedes ‘Parkinsonism’.	243
Frontotemporal dementia	2%	Specifically affects the frontal and temporal lobes of the brain resulting in changes in behaviour, and a deterioration in language and social skills. More common in people under 65 years old.	49
Parkinson’s dementia	2%	Progressive dementia seen in primary Parkinson’s patients characterised by impaired visuo-spatial abilities, impaired	49

		concentration, daytime sleepiness, visual hallucinations and delusions.	
Other	1%	Includes genetic, infective, inflammatory and neoplastic causes.	25
All			2422

Why is dementia important?

Incidence and prevalence

Current estimates suggest there are 982,000 people living with dementia (PLWD) in the UK, projected to increase to 1.4 million by 2040 (18). The incidence of dementia increases as people age, with a doubling of dementia incidence for each 6.3 year increase in age, from 3.9 per 1000 person-years at age 60-64 to 104.8 per 1000 person-years at age 90+ (19). Increased incidence in the elderly population is particularly important in Bedford Borough, where both the absolute number and proportion of the population aged 65 or older will increase in the coming decades (20). The differing prevalence of dementia in the general population and those aged 65 or over is illustrated in Figure 1.

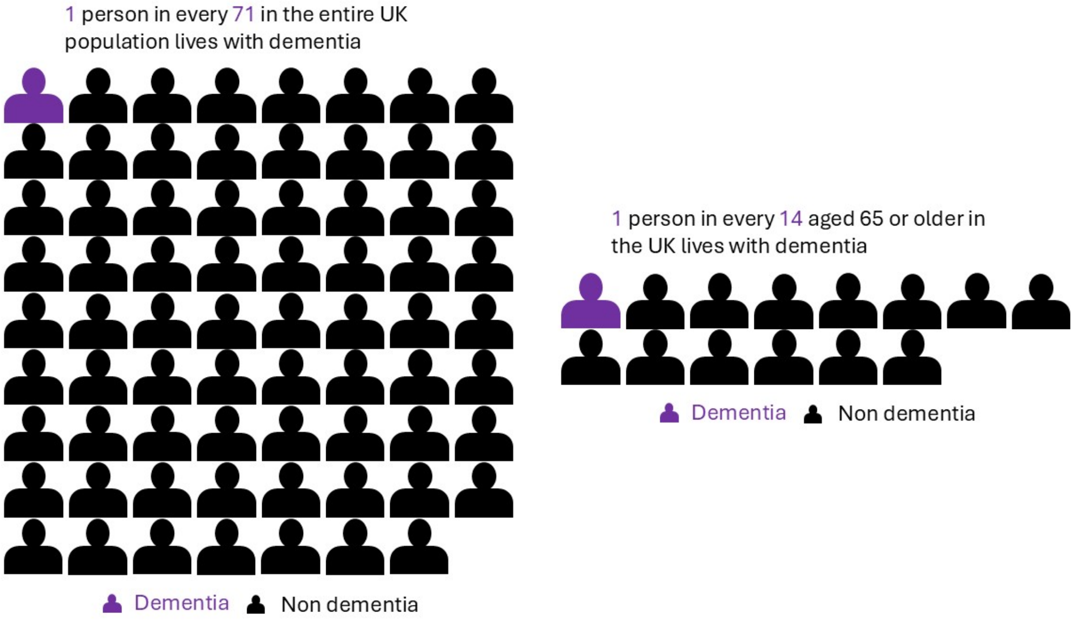

Figure 1 Prevalence of dementia in the entire UK population and those aged 65 or older. Source: Carnall Farrar/ Alzheimer's Society (18).

Inequalities

Dementia also highlights important health inequalities. The incidence of dementia varies according to several characteristics, with one's chances of developing dementia influenced by age, gender, ethnicity, disability, pre-existing conditions, socioeconomic status, sexual identity and religion or belief (21). Following a diagnosis of dementia, one may then experience inequalities secondary to the stigma associated with the condition. This may vary according to the specific context, but effects of stigma may include increased isolation from society, reduced access to healthcare and loneliness.

Cost

The cost of dementia cannot be ignored. Current estimates are that dementia costs in the UK were £42 billion in 2024 and are projected to more than double to £90 billion by 2040 (18). These estimates are based on average costs of £28,700, £42,900 and £80,500 per person per year for those living with mild, moderate and severe dementia respectively (Figure 2). The majority of these costs come from unpaid care and social care, with healthcare costs comprising a relatively small proportion. Approximately 63% of these costs are absorbed by patients and their families, leaving a significant proportion to be funded by external bodies including local authorities, health services and the voluntary sector, amongst others.

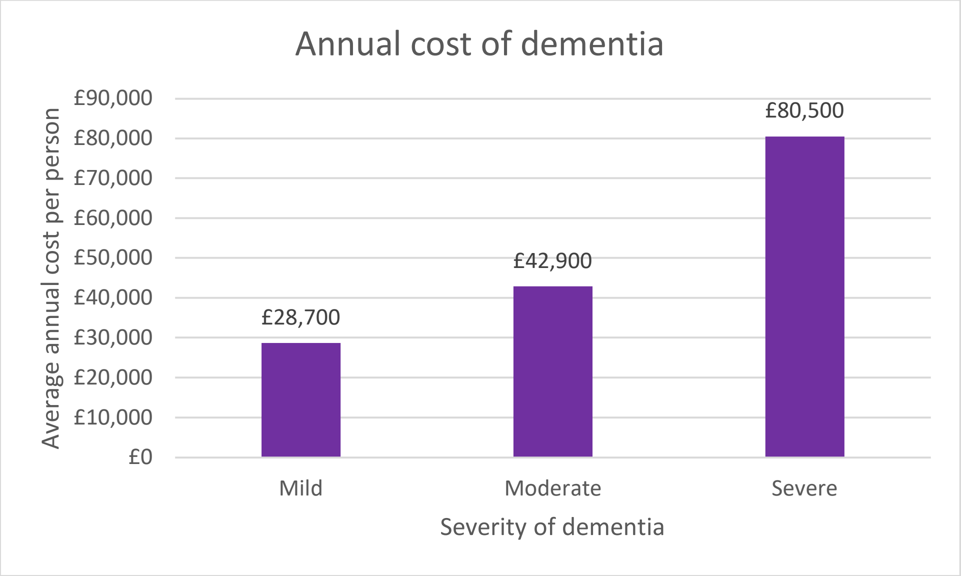

Figure 2 Average costs per person per year for mild, moderate and severe dementia. Source: Carnall Farrar/ Alzheimer's Society (18)

National context

The topic of dementia has been recognised by successive governments since the turn of the millennium.

In 2009, the Labour administration published *Living Well With Dementia: a national dementia strategy* (22). Three key areas were highlighted for improvement: improved awareness, earlier diagnosis and intervention, and a higher quality of care.

A further strategy was published in 2015 under the Conservative and Liberal Democrat coalition government, named the *Prime Minister's challenge on dementia 2020* (23). This built on the priorities of the previous administration and included achieving the following by 2020:

- Improving diagnosis, assessment and care for people living with dementia
- Ensuring that all people living with dementia have equal access to diagnosis
- Providing all National Health Service (NHS) staff with training on dementia appropriate to their role
- Ensuring that every person diagnosed with dementia receives meaningful care

Further to these strategies, the Care Act 2014 created a new legislative framework for adult social care, giving carers a legal right to assessment and support (24).

In May 2022, plans were announced to publish a 10-year plan for dementia by the end of the calendar year (25). However, no plan was released and there has subsequently been a change of health secretaries and then government. There are plans to produce a wider NHS 10 Year Health Plan for England in 2025 (26).

What is the current Health Needs Assessment trying to achieve?

A Health Needs Assessment (HNA) is a systematic method of identifying the unmet health and healthcare needs of a population, facilitating the appropriate targeting of resources (27). Benefits of such an approach include shared decision making, improved relations between key stakeholders and encouraging better use of resources. Challenges include adequate ‘buy-in’ from all involved, accessing relevant data and translating findings into effective action.

Epidemiological, comparative and corporate approaches to an HNA are most commonly used (28), and this report will attempt to combine all three:

- Epidemiological – considers the epidemiology of the condition and the quantitative needs of the population
- Comparative – compares service provision locally with best practice and other areas of the country
- Corporate – based on eliciting the views of stakeholders, which may include health and care professionals, patients and service-users and voluntary organisations.

The previous dementia HNA for Bedford Borough was published in 2016, and the recommendations helped inform local dementia services, particularly the commissioning of post-diagnostic support services. This report will aim to revisit and build on some of the key aspects of the previous HNA, helping to inform dementia services in Bedford Borough.

What is not covered by this HNA?

Any apparent limitations of this HNA are highlighted in the relevant sections. For example, in section 3 (descriptive epidemiology), several data sets were not available at the level of Bedford Borough. Where possible, the most appropriate data sources were used to provide a local estimate.

The PLWD and carers consulted as part of this HNA were those in receipt of post-diagnostic support services. This means that the perspectives of those who are not accessing care may have been excluded. Further to this, there is limited local information relating to minority ethnic communities, lesbian, gay, bisexual, transgender, queer and other (LGBTQ+) groups and prisoners. Further work should be done to engage with and elicit the views of these communities.

Finally, there is a fast-changing policy sphere surrounding dementia and health and social care more widely. This leads to continually updated strategies and guidelines which reflect the underlying evidence base and current political situation. This HNA has therefore tried to capture the current situation as best as possible, but this will be subject to change following the publication of the report.

Section 2 Primary, Secondary and Tertiary Prevention of Dementia

- Focussing on prevention can help to reduce the incidence of dementia in Bedford Borough, allow better control of symptoms once disease develops and reduce the burden on the individuals affected and wider society.
- There are at least 14 modifiable risk factors which together may reduce dementia cases by as much as 45%. Many of these are existing priorities for prevention, such as cardiovascular risk factors including cholesterol, physical activity, smoking and obesity.
- Screening is not currently recommended, as dementia cannot be reliably detected before symptoms develop. If this was possible, there are no available treatment options which could reverse the course of disease.
- Timely diagnosis is critical, however, for accessing treatment and support, which can lessen the burden of dementia and improve the quality of life for the person living with dementia and their carer(s).

The term prevention can be broken down into primary, secondary and tertiary approaches. Primary prevention involves taking action to reduce the incidence of disease and health problems within a population, either through universal measures or by targeting high-risk groups. Secondary prevention involves detecting disease in its early stages and intervening before full symptoms develop, while tertiary prevention aims to alleviate the impact of an ongoing illness.

Preventing the incidence of dementia in the first place, and then preventing poor health outcomes following diagnosis, has the potential to increase a population's quality of life and reduce the burden on the health and social care system. Focussing on prevention may therefore result in significant long-term cost savings in Bedford Borough.

This section of the report will explore dementia with regards to primary, secondary and tertiary prevention and outline some of the evidence underpinning this. The 2024 report from the Lancet Standing Commission into dementia prevention, intervention and care is highly informative and this section will attempt to summarise some of the key messages with reference to other sources of evidence where appropriate (14).

Age-specific incidence rates in many high-income countries have decreased over the past two decades, suggesting that prevention is possible (29). However, most of this decrease occurred in socio-economically advantaged areas and evidence from England is conflicting (30–32). This emphasises the importance of implementing effective preventive measures and ensuring their uptake is equitable across the whole of Bedford Borough.

Primary prevention

Primary prevention measures target modifiable risk factors, therefore risk factors such as age, sex, parental history of dementia, material deprivation and household occupancy which are included in the UK Biobank Dementia Risk Score will not be considered (33). The modifiable risk factors considered here are those identified by the Lancet 2024 Standing Commission and are proposed to prevent and delay dementia through: decreasing vascular damage, reducing dementia neuropathology, reducing stress and inflammation and building cognitive and brain reserve (Figure 3) (14). The commission proposes that if these risk factors, which can be divided into early- (up to 18 years), mid- (18 to 65 years) and late- (aged over 65 years) life, were eliminated dementia cases could be reduced by as much as 45%. Other risk factors considered by the commission but for which insufficient evidence was found include too little sleep, an unhealthy diet, infections and mental health conditions.

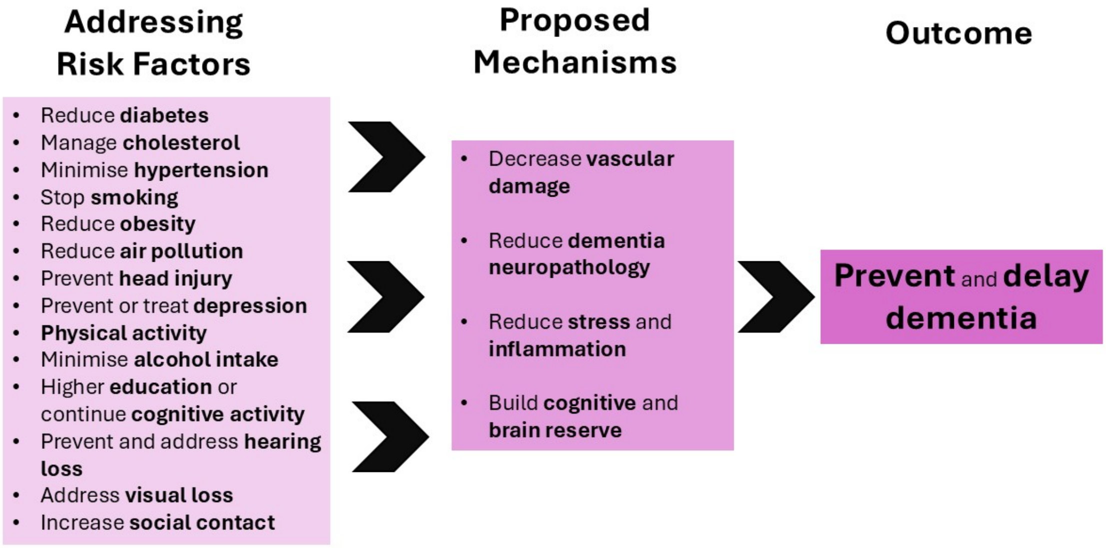

Figure 3 How addressing risk factors is proposed to prevent and delay dementia. Adapted from Figure 2, Lancet Commission 2024 (14)

Early life

Less education

Education is the only risk factor identified in early life, although it continues beyond the age of 18. Educational attainment, rather than years in education, appears to drive the protective effect for future cognition and dementia (34). Cognitive stimulation due to occupation is independently associated with reduced dementia risk (35,36).

The mechanism is unclear, with one hypothesis suggesting higher concentrations of circulating proteins facilitate brain repair or reduced decline in functional brain networks. Occupational stimulation and educational attainment may also be associated with elevated financial status, which could act as a confounding factor. A confounder affects both the main factor being studied and the outcome, making it harder to elicit if there is a direct link between them. In this case, elevated financial status may help to reduce other risk factors which also influence the risk of dementia.

The Lancet commission suggest that the evidence for cognitive training later in life is weak, with prolonged stimulation over many years (for example at work) thought to have a greater effect (35).

Midlife

Hearing loss

The Lancet commission conducted a meta-analysis (which involves estimating the overall effect across multiple different research studies) which demonstrated that hearing loss is associated with increased dementia risk. Proposed mechanisms include psychosocial factors such as loneliness, depression and social isolation. Suggested cognitive mechanisms include a reduced cognitive reserve due to additional environmental stimuli and increased cognitive resources required for listening (37).

If hearing loss is due to cardiovascular disease in the ear, this may also increase the likelihood that parts of brain linked to dementia could also be affected.

Less evidence was found by the commission regarding the protective effect of hearing aids. However, there does appear to be some evidence to support this and studies have indicated it would likely be a cost-effective intervention (38).

High Low Density Lipoprotein cholesterol

Prior to 2020, there was inconclusive evidence regarding the link between Low Density Lipoprotein (LDL) cholesterol and dementia (39). In the intervening years, a meta-analysis of three cohort studies from the UK have demonstrated a dose-dependent effect of LDL cholesterol on dementia risk (40). That is, the greater the level of circulating LDL cholesterol, the higher the risk of developing dementia. Proposed mechanisms include that excess brain cholesterol is associated with increased stroke risk and deposition of brain amyloid beta and tau, key factors in the development of dementia (40).

Statins are a class of drug recommended for the treatment of high cholesterol. When compared to people living with untreated high cholesterol, those treated with statins have been shown to have a reduced risk of all-cause dementia and AD (14).

Depression

The Lancet commission found the risk of developing dementia over 10-14 years was significantly higher in those with a diagnosis of depression versus those without. The studies examined suggest that depression increases the risk of dementia across all age groups in adulthood, although later in life some of the association is likely caused by preclinical dementia (which can cause depressive symptoms). The mechanism for this association is unclear but may include depression causing reduced self-care and social contact. Additionally, an increase in cortisol - a stress hormone which may be elevated in those living with depression - is associated with brain changes linked to dementia (41).

A study conducted in the UK found PLWD had a lower risk of developing dementia when treated with either pharmacotherapy, psychotherapy or combination therapy compared to those who received no treatment at all (42).

Traumatic brain injury

Several meta-analyses, conducted by the Lancet and others, support an increased risk of developing dementia following a Traumatic Brain Injury (TBI), with the onset of dementia typically 2-3 years earlier than those who have not suffered a TBI (39,43–45). A TBI can cause or exacerbate dementia through direct trauma to the brain, although the exact mechanism by which this occurs is unclear (46).

In higher-income countries, falls and violence are the most common cause of TBIs (as opposed to road traffic accidents in other parts of the world), with alcohol often a contributing factor (47). TBIs can also be sustained while playing sport, with some activities causing occasional severe TBIs (e.g. cycling or horse riding) while others cause more frequent concussions or mild TBIs (e.g. rugby and football). While strategies to protect against head injuries should be an individual and public health priority, this should not obscure the message that sport is generally good for health.

Physical activity

Exercise is hard to measure and there is a sliding scale involving different amounts and intensities. However, a systematic review and meta-analysis of 58 studies identified an association between physical activity and decreased risk of all-cause dementia (48). The Lancet 2024 commission comment that exercise at any age appears helpful for cognition, possibly mediated by changes in blood flow and function from reduced hypertension and increased nitric oxide (49). This may ultimately result in enhanced brain plasticity and reduced neuroinflammation, reducing dementia risk.

Smoking

In 2020, the Lancet commission found smoking in late life was associated with an increased risk of dementia. Cohort studies and meta-analyses in the years since have suggested that smoking in midlife has a greater relative effect on dementia risk (50–54). This may be due to improvements in the treatment of other smoking-related diseases, such that smokers survive long enough to develop dementia. Evidence is also emerging that current smokers, but not ex-smokers, have significantly greater risk of developing dementia versus never-smokers (55). This emphasises the beneficial effects of smoking cessation.

Diabetes

Similarly to smoking, the Lancet commission recommends Type 2 Diabetes is considered a risk factor in midlife rather than late life. This is based on evidence from a recent study demonstrating an increased risk of dementia for every 5-year decrease in the age of onset under age 70 (56). The mechanism by which diabetes influences dementia risk is uncertain but may be mediated by a vascular component (e.g. increased risk of stroke), the effect of insulin resistance on the brain and general increased diabetes-associated inflammation (56–58).

Dementia risk therefore increases with longer duration of illness and also when diabetes control is poor. Primary prevention of diabetes is therefore important, although strategies are broad and encompass many different behaviours and risk factors. The Lancet commission suggests overall improved control of diabetes may attenuate dementia risk.

Hypertension

The evidence is unclear on the exact link between hypertension and dementia. In 2020, the Lancet commission established that midlife hypertension increases the risk for all-cause dementia, despite blood pressure tending to decrease in the 5-years before diagnosis.

When used to treat high blood pressure, hypertensive medications appear to have a protective effect against cognitive impairment and dementia (59,60).

Obesity

The Lancet 2020 commission and consequent meta-analyses have identified obesity in midlife as a risk factor for dementia (61,62). Obesity is correlated with other risk factors for dementia, which means its effect could be mediated via these. However, most studies included in the aforementioned meta-analyses did adjust for possible confounders. A possible mechanism which may explain why obesity is associated with an increased risk of dementia even after accounting for risk factors is increased circulating stress hormones and inflammation associated with the stigma of living with a high BMI (63).

Weight loss of as little as 2kg has been shown to be associated with improvements in cognition, according to a meta-analysis (64). Weight loss through behaviour change, such as by eating more healthily or increasing physical activity, has a more pronounced association than in people who have had bariatric surgery (65).

Excessive alcohol consumption

Meta-analyses have shown that drinking more than 21 UK units of alcohol per week in midlife is associated with an increased risk of dementia when compared to those who drink less than this (39,66).

Evidence that abstinence decreases dementia risk is less clear, which may be due to various factors. One is that any link between not drinking and developing dementia is due to survivor bias (i.e. those who abstain are more likely to live long enough to develop dementia which artificially inflates the risk) (67). Additionally, people defined in a study as not drinking alcohol may not drink due to the presence of other risk factors e.g. a learning disability which independently increases dementia risk or because they have been a heavy drinker in the past. Studies correcting for previous high alcohol consumption have reported no excess mortality in the non-drinking group (68,69).

Late life

Social isolation

The Lancet commission reports that infrequent social contact (an objective measure, although with various definitions) and loneliness (subjective according to an individual) are both associated with increased dementia incidence. Social contact is proposed to protect against dementia by building cognitive reserve, promoting healthy behaviours, and reducing stress and inflammation (70). Reverse causation must be considered here, as dementia itself may lead to withdrawal from social activities.

No clear evidence exists yet on whether this risk appears to be reversed in those taking part in interventions to increase social contact. So far, studies have been small with short follow-up periods.

Air pollution

Evidence that air pollution (particularly $PM_{2.5}$ i.e. fine particles with a diameter $\leq 2{\cdot}5$ µm) is associated with an increased risk of dementia, has increased in the years following 2019 and is acknowledged by the Lancet commission.

Several studies have suggested that when efforts have been made to reduce air pollution, a reduction in dementia risk amongst the population has followed (71–74). World Health Organisation guidelines on air quality stipulate mean annual $PM_{2.5}$ concentrations should be less than 5 $\mu g/m^3$ (75). However, it is unclear if any safe concentration of air pollution exists, given every 1 $\mu g/m^3$ increase in $PM_{2.5}$ is associated with increased dementia risk (76).

Untreated visual loss

The final risk factor identified by the 2024 Lancet commission was untreated visual loss. Hypothesised mechanisms include underlying illness, such as diabetes, which is also a risk factor for dementia (39). There may also be shared pathological processes between the retina, which is part of the eye, and the brain (77).

There is some evidence that treatments such as cataract surgery are associated with a reduced risk of dementia, but this is not consistent (78,79).

Secondary prevention

Despite the scarcity of effective treatment for dementia, interventions to mitigate cognitive decline do exist therefore it is still advantageous to detect dementia in a timely fashion so that treatment can be initiated. A diagnosis is also important in order to access some support services.

If a diagnosis is made, it is usually some time after symptoms have first been noticed by friends and family. Barriers to diagnosis include (80):

- Denial
- Stigma
- Fear
- Lack of knowledge
- Normalisation of symptoms
- Desire to preserve autonomy
- Lack of perceived need
- Not noticing changes
- Lack of family and friend support network
- Carer's difficulties
- Problems accessing help
- Lack of preparedness of services to make a diagnosis

Enablers include recognition of dementia symptoms, previous knowledge and contacts, and support from informal networks.

The UK National Screening Committee is responsible for making recommendations on screening programmes in the UK. The last review on dementia, published in 2019, recommended against screening for dementia (81) due to:

- No available screening tests which would be able to find people living with dementia before they show symptoms
- No evidence that treatments for dementia are effective
- Concern about how people diagnosed by screening may be affected by dementia related screening

The 2024 Lancet Standing Commission outlines several diagnostic tests, including neuro-imaging, biomarkers in the cerebrospinal fluid and blood, as well as genetic tests which could be used as screening tests in the future. However, much more work is needed to refine biomarkers and ensure they are clinically meaningful. Additionally, most research has taken place in white populations which raises questions over generalisability.

Tertiary prevention

Following a diagnosis of dementia, there are several steps that can be taken to help people continue their everyday lives as much as possible and preserve their quality of life. As described above, there are no current therapies which can reverse the course of this disease therefore efforts are focussed on primary prevention and providing appropriate support following a timely diagnosis.

National Institute for Health and Care Excellence (NICE) guidance emphasises the importance of tertiary prevention, with many of its recommendations focussed on mitigating the ongoing impact and consequences resulting from a dementia diagnosis (82).

Important aspects of tertiary prevention include the following:

- Management of existing medical conditions which are associated with dementia, such as hypertension and diabetes, is important to prevent the worsening of an individual's condition.
- Preventing and treating infections is particularly important in older people, including those living with dementia. This is due to the possibility of delirium, acute confusion which can arise from infection, which may cause distress to the individual and their carer should it be superimposed on dementia.
- Responding to and treating symptoms of dementia is also important. In many cases, this can be done without medication, for example through Cognitive Behavioural Therapy (CBT). The management of medication remains important, however, both in regard to initiating pharmacological therapy which provides benefits and stopping any which may cause harm.
- The wider environment must also be considered, with accommodations put in place for safety purposes, to prevent falls and maintain independence. This includes the use of supportive and social services, which may assist individuals in performing activities of daily living, engaging in physical activity, taking part in meaningful activities and socialising with others. The nutrition and hydration of PLWD should also be attended to, and family carer needs must be considered.

NICE have produced two guidelines on dementia: *NG16: Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset* and *NG97: Dementia: assessment, management and support for people living with dementia and their carers* (82,83). These will not be explored in detail here, but adherence to best practice will be considered in making recommendations.

Section 3 Descriptive Epidemiology

- There were approximately 1,500 people registered as living with dementia in Bedford Borough in 2024. However, it is estimated that more than 3 in every 10 people living with dementia are undiagnosed, meaning there may be almost 2,500 people truly living with dementia.
- Dementia is the leading underlying cause of death in England and Wales. The rate of death from dementia is not significantly different in Bedford Borough when compared to the England average.
- The number of people living with dementia in Bedford Borough is forecast to increase between 54% and 86% between 2023 and 2043, depending on the assumptions of the forecasting model. This is equivalent to approximately 1,500 additional people living with dementia.

Incidence

Incidence is a measure of new cases of a disease within a specified population in a specified time period. The smallest geographical level at which incidence is calculated is the regional level i.e. East of England. Figures from 2023 show at the regional level, the East of England has a relatively high incidence of new dementia cases each year in people aged 65 or over at 880 (95% CI 860-900) per 100,000 people at risk, significantly higher than most other regions (Table 2, Figure 4). Applying the regional incidence rate to Bedford Borough, using 2023 mid-year Office for National Statistics (ONS) population estimates, equates to 6 new cases of dementia each week.

Table 2 Estimated dementia incidence rates per 100,000 people at risk per year. NHS Regions, December 2023 estimate, people aged 65 and over (source: DHSC Dementia New Indicators Factsheet April 2023 to December 2023 (84))

Region	Incidence rate per 100,000 people (95% Confidence Interval)
London	740 (730-760)
South East	790 (780-800)
North East and Yorkshire	820 (800-830)
Midlands	830 (810-840)
South West	850 (840-870)
North West	860 (850-880)
East of England	**880 (860-900)**
England	820

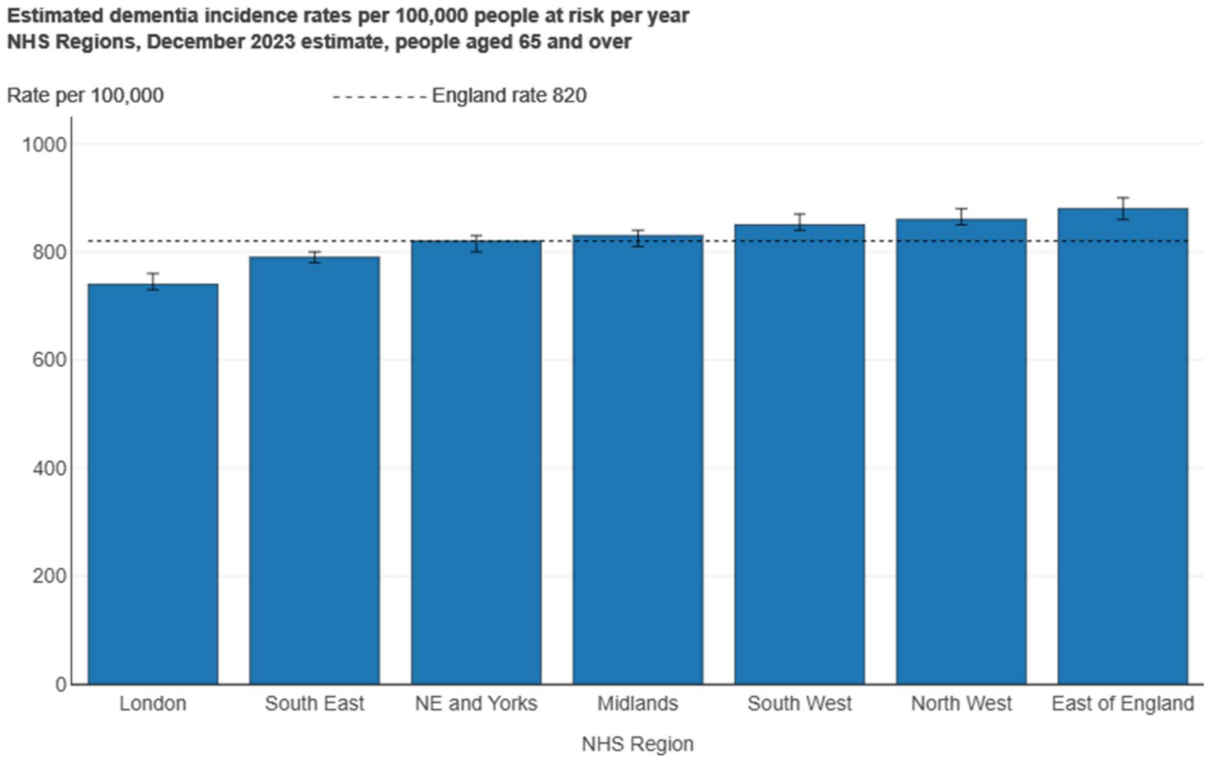

Figure 4 Estimated dementia incidence rates per 100,000 people at risk per year. NHS Regions, December 2023 estimate, people aged 65 and over (source: DHSC Dementia New Indicators Factsheet April 2023 to December 2023 (84))

Prevalence

Prevalence is a measure of the proportion of a specified population which has a condition at a specified point in time. Dementia prevalence is challenging to calculate as the true number of PLWD includes those both diagnosed and undiagnosed.

This report will present two estimates of prevalence, one derived from nationally recorded General Practice (GP) data and another estimate calculated using additional data produced for the local 2025 Director of Public Health (DPH) report. Both estimates calculate prevalence based only on those diagnosed with dementia. True prevalence estimates will be presented in relation to estimated diagnosis rates and forecasting data.

GP practice disease registers

The recorded prevalence in those aged 65+ is calculated using patients registered with dementia on GP practice registers and presenting these as a proportion of the total practice list size for people aged 65+. These figures are available up to 2020. From 2017-2020, the number of registered patients aged 65+ with dementia increased slightly from 1,180 to 1,305, and prevalence also increased slightly from 4.02% to 4.23%, although this increase is not significant. The prevalence figures are broadly in line with regional and national estimates (Table 3, Figure 5).

Table 3 Number of registered patients aged 65+ with dementia in Bedford Borough and recorded prevalence (with 95% confidence intervals) in Bedford Borough, East of England and England. Source: Fingertips Dementia Profile (85)

Year	Number of patients (aged 65+) registered as living with dementia in Bedford Borough	Bedford Borough recorded prevalence, % (95% Confidence Interval)	East of England recorded prevalence, % (95% Confidence Interval)	England recorded prevalence, % (95% Confidence Interval)
2017	1,180	4.02 (3.80-4.25)	4.11 (4.07-4.14)	4.33 (4.32-4.35)
2018	1,236	4.14 (3.92-4.37)	4.22 (4.19-4.26)	4.32 (4.31-4.34)
2019	1,355	4.44 (4.21-4.67)	4.26 (4.22-4.29)	4.34 (4.32-4.35)
2020	1,305	4.23 (4.01-4.46)	3.95 (3.92-3.99)	3.97 (3.96-3.99)

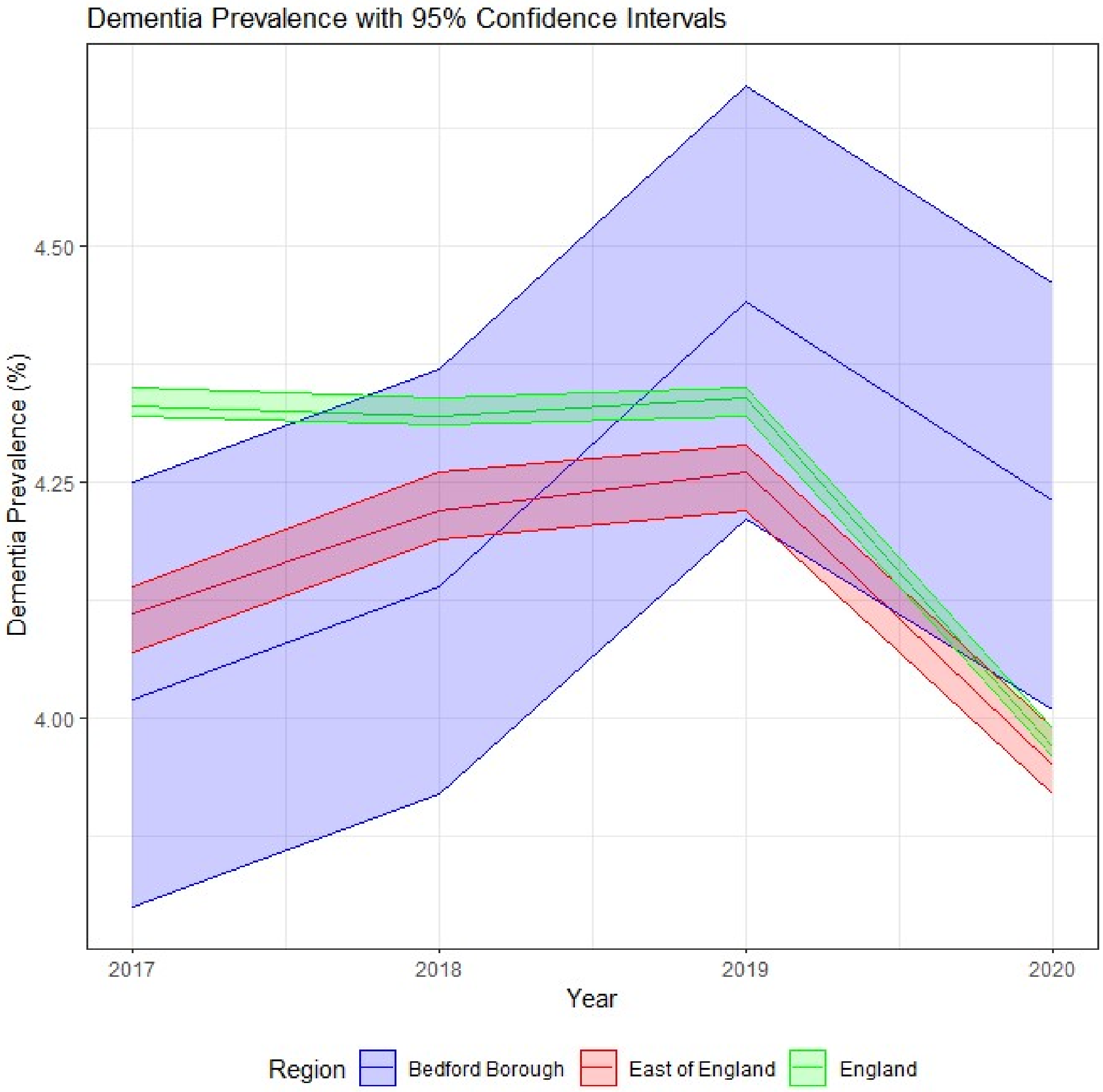

Figure 5 Recorded prevalence aged 65+ (with 95% confidence intervals) in Bedford Borough, East of England and England based on GP dementia register and practice list size. Source: Fingertips Dementia Profile (85)

All health records (including primary care data)

The estimate of dementia prevalence calculated by NHS Arden and Greater East Midlands Commissioning Support Unit (AGEM CSU) for the Bedford Borough 2025 DPH Report used data from all health records, not exclusively primary care data as in the previous estimate. The earliest prevalence estimate was for 2023 as this piece of work primarily focussed on forecasting. An estimated 1,634 people had a recorded diagnosis of dementia in 2023, giving a prevalence figure of 0.89% in the whole population and 4.92% in those aged 65 and over (Table 4). This prevalence figure is slightly higher than the most recent year calculated using only GP practice data.

Table 4 Number of people living with dementia in Bedford Borough and associated prevalence estimates, 2023. Source: NHS AGEM CSU

Number of people living with dementia in Bedford Borough in 2023	Prevalence in all age groups	Prevalence in people aged 65+
1,634	0.89%	4.92%

Diagnosis rate

The diagnosis rate considers the estimated true prevalence of dementia in a population and uses this to estimate the proportion of true dementia cases diagnosed. Diagnosis rates use prevalence estimates calculated from the Cognitive Function and Ageing Study II (CFAS II) and adjusts for the age and sex distribution of the relevant population. The overall estimate of prevalence in those aged 65 years and over from the CFAS II study is 6.4% (86). Limitations of this method include that it does not appear to directly adjust for other population demographics relevant to dementia prevalence, including deprivation and ethnicity.

The NHS England target for dementia diagnosis is to diagnose 66.7% of cases. A Red-Amber-Green (RAG) rating system is used to score dementia diagnosis rates, with Red representing significantly lower (worse) than the target, Amber representing not significantly above or below the target and Green representing significantly higher (better) than the target. Bedford Borough has appeared consistently amber from 2017 to 2024, although the diagnosis rate has increased from 62.1% to 68.5% (Table 5).

Table 5 Diagnosis rate in Bedford Borough compared to national benchmark of 66.7% and national rates. 95% confidence intervals included. Red represents significantly lower (worse) than the benchmark, Amber not significantly above or below and Green significantly higher (better). Source: Fingertips Dementia Profile (85)

Year	Diagnosis rate, % (95% Confidence Interval) in Bedford Borough	Diagnosis rate, % (95% Confidence Interval) in England
2017	62.1 (55.0-68.4)	67.9 (61.2-73.6)
2018	60.9 (53.9-67.0)	67.5 (60.8-73.1)
2019	64.5 (57.2-71.0)	68.7 (61.9-74.4)
2020	69.1 (61.5-75.9)	67.4 (60.7-73.0)
2021	64.3 (57.1-70.7)	61.6 (55.5-66.7)
2022	63.5 (56.3-69.7)	62.0 (55.8-67.1)
2023	67.1 (59.6-73.7)	63.0 (56.8-68.3)
2024	68.5 (60.9-75.2)	64.8 (58.3-70.2)

Mortality

Local mortality rates for dementia are available, while national figures are produced on the leading underlying causes of death. Identifying the role of dementia at the end of life is challenging. Death certification is to some degree subjective, and national estimates suggest less than 25% of people with a dementia diagnosis have this recorded on their death certificate (87). This may therefore lead to underestimates of the influence of dementia on mortality.

Local mortality rates

Local estimates have been produced for the direct standardised mortality rate of dementia for people aged 65 and over from 2016-2019 (Table 6). This uses data on the number of deaths with a mention of dementia or AD (either as an underlying or contributory cause) and expresses the mortality rate per 100,000 people in a 'standard' population. This allows different areas to be compared, even if the numbers of people in different age brackets varies. From 2016-2018, the mortality rate from dementia in Bedford Borough was significantly below the English national average (ranging from 712 to 787 per 100,000 population) but increased in the most recent reporting year of 2019 to 817 per 100,000 population (95% CI 722-920 per 100,000 population), bringing it in line with the England average.

Table 6 Direct standardised rate of mortality from dementia (dementia or Alzheimer's as underlying or contributory cause) per 100,000 population aged 65 years and over. Number of dementia deaths in Bedford Borough, Bedford Borough mortality rate and England mortality rate. Source: Fingertips Dementia Profile (85)

Year	Number of dementia deaths in Bedford Borough	Bedford Borough Mortality Rate (95% Confidence Interval)	England Mortality Rate (95% Confidence Interval)
2016	221	712 (621-813)	866 (860-871)
2017	245	787 (691-893)	901 (895-907)
2018	237	735 (644-835)	904 (898-910)
2019	272	817 (722-920)	849 (844-855)

All deaths registered in England and Wales

The ONS records data on the underlying cause of death for all ages (excluding under one year) by gender across England and Wales. The most recent complete year, 2023, shows dementia and AD is the leading underlying cause of death, accounting for 11.6% of all deaths (Table 7, Figure 6). Dementia and AD has been the leading underlying cause of death for females in each of the past three years, including during the COVID pandemic, while it is the second leading underlying cause of death for males, behind ischaemic heart disease (IHD) (and was the third leading cause of death behind COVID-19 and IHD during the COVID-19 pandemic).

Table 7 Leading underlying causes of death in England and Wales from 2021-2023 in all ages (excluding under 1 year) by gender and combined. Source: ONS (88)

Year	Group	Leading underlying cause of death	Number of deaths	Percentage (%)
2023	All	Dementia and Alzheimer's disease	66,876	11.6
		Ischaemic heart diseases	57,895	10.0
		Chronic lower respiratory diseases	32,106	5.5
	Male	Ischaemic heart diseases	38,376	13.1
		Dementia and Alzheimer's disease	23,994	8.2
		Chronic lower respiratory diseases	15,908	5.4
	Female	Dementia and Alzheimer's disease	42,882	15.1
		Ischaemic heart diseases	19,519	6.9
		Chronic lower respiratory diseases	16,198	5.7
2022	All	Dementia and Alzheimer's disease	65,967	11.5
		Ischaemic heart diseases	59,356	10.3
		Chronic lower respiratory diseases	29,815	5.2
	Male	Ischaemic heart diseases	38,730	13.3
		Dementia and Alzheimer's disease	23,332	8.0
		Lung cancer	14,855	5.1
	Female	Dementia and Alzheimer's disease	42,635	15.0
		Ischaemic heart diseases	20,626	7.3
		Cerebrovascular diseases	16,223	5.7
2021	All	COVID-19	67,348	11.5
		Dementia and Alzheimer's disease	61,250	10.5
		Ischaemic heart diseases	56,959	9.8
	Male	Ischaemic heart diseases	37,094	12.5
		COVID-19	36,792	12.4
		Dementia and Alzheimer's disease	21,000	7.1
	Female	Dementia and Alzheimer's disease	40,250	14.0
		COVID-19	30,556	10.6
		Ischaemic heart diseases	19,865	6.9

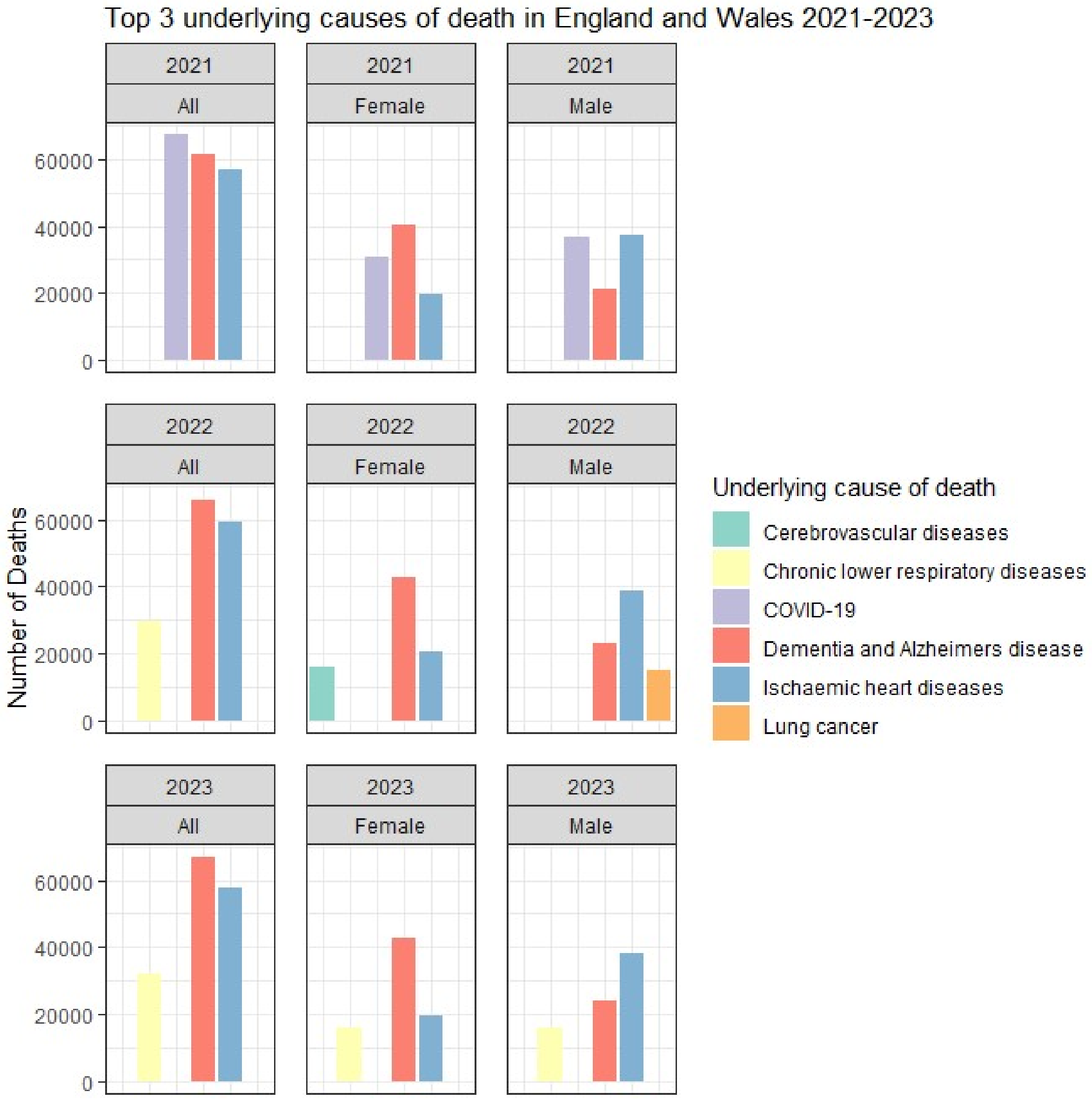

Figure 6 Leading underlying causes of death in England and Wales from 2021-2023 in all ages (excluding under 1 year) by gender and combined. Source: ONS (88)

Forecasting

Forecasting changes to the number of PLWD and future prevalence can provide a sense of the burden of this disease in years to come. Forecasts have been produced by NHS AGEM CSU, using data described previously, and also by the Projecting Older People Population Information (POPPI) system. Both will be presented here.

Projections made by NHS AGEM CSU

NHS AGEM CSU made age-sex crude prevalence forecasts for dementia up to 2043 for the 2025 Bedford Borough DPH report under differing scenarios of future prevalence. The different scenarios included decreased prevalence (0.1% decrease in prevalence per year), higher prevalence (0.1% increase in prevalence per year) and much higher prevalence (0.2% increase in prevalence per year). The values for 2023 (as presented earlier under prevalence) and 2043 – for base prevalence, lower prevalence and much higher prevalence are presented in Table 8 and Figure 7. The forecasts, even accounting for uncertainty in future prevalence, predict the absolute number of PLWD in Bedford Borough will almost double from 1,634 to 3,046 (range of 2,986-3,170 under different prevalence scenarios) over 20 years from 2023 to 2043. This is despite only a relatively mild increase in prevalence in people aged 65 and older, in whom dementia is most common, from 4.92% to 5.68% (range of 5.56-5.91% under different prevalence scenarios). This demonstrates the likely increase in PLWD in years to come, due to a growing and ageing population.

Table 8 Forecast number of people living with dementia and dementia prevalence in people aged 65 and older in 2023 and 2043 in Bedford Borough. Base prevalence (no change in prevalence of dementia), lower prevalence (0.1% decrease per year in prevalence of dementia) and much higher prevalence (0.2% increase per year in prevalence of dementia) scenarios shown. Source: NHS AGEM CSU

Absolute number of people living with dementia (all ages)				**Prevalence of people living with dementia (aged 65 and older), %**			
2023	2043 (base prevalence)	2043 (lower prevalence)	2043 (much higher prevalence)	2023	2043 (base prevalence)	2043 (lower prevalence)	2043 (much higher prevalence)
1,634	3,046	2,986	3,170	4.92%	5.68%	5.56%	5.91%

POPPI projections

POPPI have projected the total population aged 65 and over predicted to have dementia in Bedford Borough up to 2040. This is calculated using age-band prevalence rates from *Alzheimer's Society's* Dementia UK: Update (2014) and applying them to ONS population projections (89,90). The prevalence estimates used are for 'true' prevalence (i.e. diagnosed and undiagnosed cases) as opposed to the figures produced by NHS AGEM CSU which use estimates of recorded prevalence. This means the estimated number of PLWD is higher, as the prevalence rate used is 7.1% as opposed to the range of 4.92-5.91% in the previous estimates. These projections forecast that the number of PLWD in Bedford Borough will increase from 2,422 in 2023 to 3,730 in 2040, a higher number than predicted by NHS AGEM CSU but a comparatively smaller relative change (Table 9, Figure 7).

Table 9 People aged 65 and over predicted to have dementia, 2023 to 2040, in Bedford Borough. Source: POPPI (data extracted on 15/10/2024) (17)

Estimated number of people living with dementia (aged 65 and older)				
2023	2025	2030	2035	2040
2,422	2,573	2,908	3,324	3,730

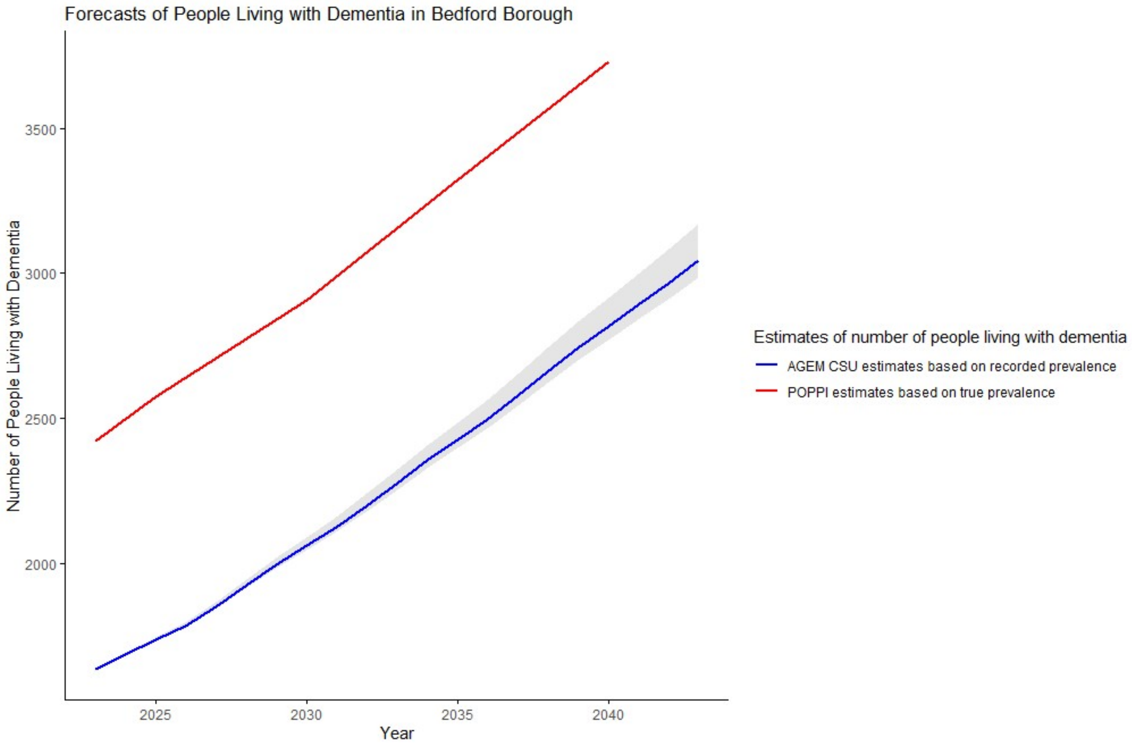

Figure 7 Forecasts of the number of people living with dementia in Bedford Borough between 2023 and 2043. NHS AGEM CSU estimates shown in blue and based on recorded prevalence, with shaded area denoting lower prevalence (0.1% decrease per year in prevalence of dementia) and much higher prevalence (0.2% increase per year in prevalence of dementia) scenarios. POPPI estimates shown in red and based on true prevalence (in those aged 65 and over only) (17).

Healthcare usage forecasts

Healthcare usage by different patient groups has been forecast as part of the Bedford Borough Council (BBC) 2025 DPH report and Dementia and AD has been included within this (Table 10, Figure 8). This uses data from NHS AGEM CSU on all health care records to forecast changes in healthcare use between 2023 and 2043. These estimates related to all healthcare use, not only healthcare use directly related to a patient’s dementia or AD diagnosis. All the metrics approximately double (in line with dementia prevalence forecasts), with the increase in primary care consultations for PLWD and AD particularly notable, from 24,535 to 45,807. This could place a significant burden on primary care services in Bedford Borough.

Table 10 Healthcare use forecasts for people living with Dementia and Alzheimer's in Bedford Borough from 2023 to 2043. Source: NHS AGEM CSU

Healthcare use	**Year**			
	2023	**2028**	**2033**	**2043**
AE Attendances	1,642	1,931	2,306	3,071
Elective Admissions	455	537	620	808
Emergency Admissions	951	1,115	1,341	1,789
Mental Health Inpatient Spells	4	4	5	6
Mental Health Occupied Bed Days	356	358	426	510
OP Attendances	5,112	6,020	7,101	9,357
Other Non-Elective Admissions	6	7	8	11
Primary Care Consultations	24,535	28,812	34,280	45,807
Grand Total	33,061	38,784	46,087	61,359

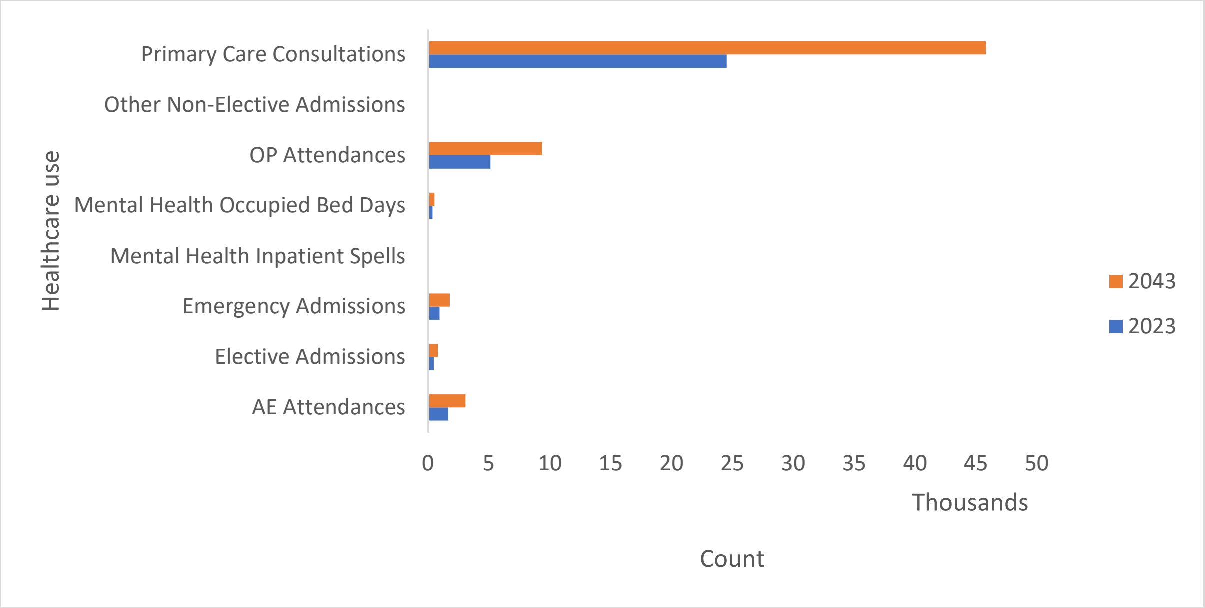

Figure 8 Healthcare use forecasts for people living with Dementia and Alzheimer's in Bedford Borough in 2023 and 2043. Source: NHS AGEM CSU

Dementia in primary care

Data is available from primary care providers on the numbers of people who are assessed for dementia, as well as the number of people who have had their care reviewed in the last 12 months.

Data was available only from 1 April – 30 June 2024 on the numbers of people assessed for Dementia in Bedford Borough (Table 11). Extrapolated to 12 months, it is expected that in a year 892 people would receive dementia assessments by their GP, 232 of whom receive an initial memory assessment (by the GP), following which 96 are referred to the memory clinic for further assessment.

Table 11 Summary table of those in Bedford Borough who have received dementia assessment, initial memory assessment and referral to memory clinic by their GP between 1 April and 30 June 2024. Per annum forecasts generated by multiplying the 3 monthly figures by 4. Source: NHS Digital (91)

Time period	Received dementia assessment by GP	Received initial memory assessment after dementia assessment	Referred to memory clinic after dementia assessment
1 April - 30 June 2024	223	58	24
2024 per annum (expected)	892	232	96

Approximately two-thirds (998, 64.8%) of patients registered with dementia were recorded as receiving a dementia care plan review in the 12 months to the end of June 2024 (Table 12). The numbers of those receiving medication reviews were only recorded for the 3 months prior to publication, but if extrapolated to 12 months almost all (99%) of those receiving care plan reviews were also having medication reviews.

Table 12 Summary table of Bedford Borough dementia register (0-64 and 65+ combined) and the number of people who have had a dementia care plan review/ declined a care plan review/ received a medication review in the 12 months up to 30 June 2024 (4 months for medication reviews). Source: NHS Digital (91)

Dementia register (all ages) as of 30 June 2024	Number of patients refusing dementia care plan or care plan review in 12 months to 30 June 2024 (% of all dementia patients)	Number of patients receiving dementia care plan or care plan review in 12 months to 30 June 2024 (% of all dementia patients)	Number of patients receiving dementia care plan or dementia care plan review in last 12 months who also received a medication review (1 April – 30 June 2024 only)
1,539	42 (2.7%)	998 (64.8%)	248

Dementia in different populations

At the Bedfordshire, Luton and Milton Keynes Integrated Care Board (BLMK ICB) level, data is available on the prevalence of dementia within different populations. This includes how dementia is recorded across different ethnic groups, prevalence of different dementia subtypes, types of residence PLWD occupy and whether PLWD have comorbidities or are on the palliative care register. More local data is also available on how many people with a learning disability are recorded as living with dementia.

Dementia in different ethnic groups

As of August 2024, where ethnicity was coded in BLMK ICB, 66% of PLWD were classified White, 6.5% Asian/ Asian British, 1.4% Black/ African or Caribbean/ Black British, 1.5% Other ethnic groups and 0.6% mixed or multiple ethnic groups (Table 13). Ethnicity was either not defined, not stated or inconclusive (more than one ethnic group recorded on the patient record on the same date) in 24.1% of cases.

Table 13 Recorded diagnoses of dementia in different ethnic groups in BLMK. Percentages will not sum to 100 due to rounding. August 2024. Source: NHS Digital (92)

Ethnic group	People living with dementia (percentage of all cases) as of August 2024
White	4,993 (66.0%)
Asian/ Asian-British	490 (6.5%)
Black/ African or Caribbean/ Black British	104 (1.4%)
Other ethnic group	115 (1.5%)
Mixed or multiple ethnic groups	43 (0.6%)
Not defined/ not stated/ inconclusive	1,825 (24.1%)

Prevalence of different dementia types

Recorded diagnoses by dementia type are also available from August 2024 at the BLMK ICB level (Table 14). Where the type was recorded, the most common was AD (42.3%), followed by Vascular Dementia (9.8%), Lewy Body Dementia (LBD) (2.4%) and Frontotemporal dementia (0.4%). 3.6% of cases were recorded as having mixed dementia types and, similarly to ethnicity, a large proportion (41.3%) were coded as ‘other’ or ‘inconclusive’, with many likely belonging to the aforementioned groups.

Table 14 Cases of dementia by type of dementia in BLMK. Percentages will not sum to 100 due to rounding. August 2024 Source: NHS Digital (92)

Type of dementia	Number of cases (percentage of all cases) as of August 2024
Alzheimer's disease	3,205 (42.3%)
Vascular dementia	745 (9.8%)
Lewy body dementia	185 (2.4%)
Frontotemporal dementia	30 (0.4%)
Mixed dementia types	275 (3.6%)
Other dementia types/ inconclusive	3,130 (41.3%)

Residence of people living with dementia

The most common recorded residence type among dementia cases in BLMK as of August 2024 is private residences (38.2%), followed by residential care homes (30.6%) and nursing homes (2.9%) (Table 15). There is a significant proportion where residence is recorded as ‘other’, or ‘inconclusive’ (28.2%).

Table 15 Recorded residence type among recorded cases of dementia in BLMK. August 2024. Source: NHS Digital (92)

Residence type	Number of cases (percentage of all cases) as of August 2024
Private residence	2,895 (38.2%)
Residential care home	2,315 (30.6%)
Nursing home	220 (2.9%)
No permanent address	5 (0.1%)
Other/ inconclusive	2,135 (28.2%)

People living with dementia who have other comorbidities

Data is available from August 2024 at the BLMK ICB level on the number of PLWD aged 65 and older who also have a listed comorbidity (i.e. one or more of diabetes, stroke, hypertension and coronary heart disease), or are listed on the palliative care register (i.e. those identified as having end of life care needs) (Table 16, Figure 9). Almost 76% of PLWD aged 65 and older in BLMK ICB are estimated to be living with at least one comorbidity, slightly above the regional and national estimates. However, the percentage of PLWD aged 65 and older who are on the palliative care register is below regional and national estimates, at 14.1%.

Table 16 Numbers of people aged 65 and older living with dementia in BLMK ICB, East of England and England who also live with at least one comorbidity or are on the palliative care register. Both shown as a percentage of all people living with dementia aged 65 and older. August 2024. Source: NHS Digital (92)

Area	People living with dementia and at least one comorbidity (percentage of all people living with dementia aged 65+) as of August 2024	People living with dementia who are on the palliative care register (percentage of all people living with dementia aged 65+) as of August 2024
BLMK ICB	5,525 (75.9%)	1,025 (14.1%)
East of England	42,790 (73.0%)	11,312 (19.3%)
England	349,493 (73.2%)	90,807 (19.0%)

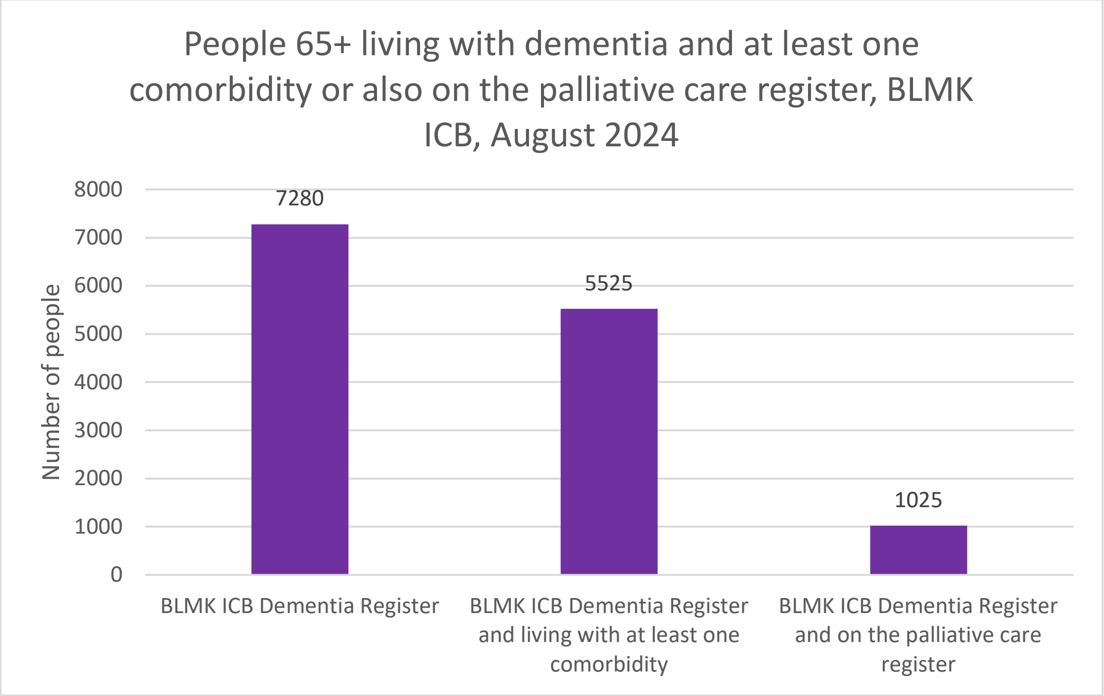

Figure 9 Numbers of people aged 65 and older living with dementia in BLMK ICB who also live with at least one comorbidity or are on the palliative care register. August 2024. Source: NHS Digital (92)

Dementia in those with Learning Disabilities

Data is available up to March 2023 on all those on the learning disability register in Bedford Borough with a recorded diagnosis of dementia (Table 17). The most recent number is 23 cases (March 2023), up from 17 the previous year.

Table 17 Number of people on learning disability register in Bedford Borough with a recorded diagnosis of dementia. Source: SystmOne

Date	People on learning disability register with recorded diagnosis of dementia
March 2023	23
March 2022	17

Dementia in the prison population

HMP Bedford has a total capacity of 394. As of December 2024, there were 9 prisoners over the age of 65. During the whole of 2024, there were a total of 9 prisoners diagnosed with dementia in HMP Bedford, although only 1 was resident as of December 2024. HMP Bedford is a remand prison which means that there are more arrivals and departures relative to other prison settings.

A study from 2020 estimated the prevalence rate of suspected dementia and Mild Cognitive Impairment (MCI) in the prison population aged 50 years or older in England and Wales at 8%, with less than half having a relevant diagnosis in their healthcare notes (93). Prevalence rates in prisons were estimated to be two times higher among individuals aged 60-69 years and four times higher in those aged 70 or older when compared to those living in the community.

Risk factors

The 14 modifiable risk factors identified in Section 2 will now be presented in the context of Bedford Borough, grouped into early-, mid- and late-life. Applying the almost 50% reduction to dementia cases in Bedford Borough could significantly reduce the burden on healthcare services now and in the future.

Early life (up to 18 years)

Less education

Three routine data sources are available regarding education in Bedford Borough, the Average Attainment 8 score; the proportion of 16- to 17-year-olds not in education, employment or training (NEET) and census data on people's highest qualification.

The Average Attainment 8 score measures the achievement of pupils in all state-funded schools at the end of Key Stage 4 (i.e. at 15-16 years old) across 8 qualifications. The provisional mean score in Bedford Borough in 2023/24 was 44.8, compared to the England average of 44.2.

The proportion of 16- to 17-year-olds NEET or whose status was not known in 2022/23 was 3.7% (95% CI 3.16-4.32%) in Bedford Borough, significantly below the average across other local authorities in the same (i.e. fourth least deprived) deprivation decile and the England average (Table 18). The 2023/24 figure for Bedford Borough shows a fall in the number of 16 and 17 year olds who are NEET to 3.14%.

Table 18 Numbers of 16- and 17-year-olds not in education, employment or training (NEET) or whose activity was not known in 2022/23, as a count and proportion (including 95% confidence interval) in Bedford Borough, all local authorities in the fourth least deprived decile (IMD 2019) and England. Source: Fingertips Public Health Profiles (94)

Area	Number of 16- and 17-year-olds NEET in 2022/23	Percentage of all 16- and 17-year-olds (95% confidence intervals)
Bedford Borough	150	3.7 (3.16-4.32)
Local authorities in the fourth least deprived decile	8,570	5.4 (5.28-5.50)
England	64,880	5.2 (5.21-5.29)

The 2021 census collected data on individual's highest qualification (Table 19). Bedford Borough has a smaller percentage of people with no qualifications (16.8%) compared to regional and national averages and higher numbers of people with the highest-level qualifications i.e. level 4 and above (34.7%).

Table 19 2021 census data on individual's highest qualification in Bedford Borough, East of England and England expressed as percentages. Percentages may not sum due to rounding. Source: Official Census and Labour Market Statistics (90)

Highest qualification	Percentage in Bedford Borough	Percentage in East of England	Percentage in England
No qualifications	16.8	18.1	18.1
Level 1 and entry level qualifications	10.4	10.8	9.7
Level 2 qualifications	13.5	14.4	13.3
Apprenticeship	5.6	5.5	5.3
Level 3 qualifications	16.2	16.8	16.9
Level 4 qualifications or above	34.7	31.6	33.9
Other qualifications	2.9	2.8	2.8

Midlife (18 to 65 years)

Hearing loss

There is little local data available on hearing impairment. The current UK estimate for the number of people with hearing loss (aged 18-80 with a loss of at least 35dB in their better ear) is 4.6 million, estimated using population data from the 2021/2022 UK censuses and prevalence data from the UK National Study of Hearing (95,96).

Applying this figure to Bedford Borough, assuming hearing impairment is evenly distributed throughout the UK, would give 12,829 people with hearing loss. It is estimated only 1 in 3 people with hearing loss are adequately treated, which would mean there are 8,553 people with hearing loss at higher risk of developing dementia (97).

High LDL cholesterol

Cholesterol levels are measured in several targeted populations, for example among people with diabetes or those attending health checks. However, they are not routinely collected at the local authority level across the whole population.

The Health Survey for England (HSE), which aims to monitor trends in the nation's health and care amongst the general population, measures cholesterol at the national level. The most recent estimate for England, using data from 2021/22, was that total cholesterol (LDL and H(igh)DL) was raised in 59% of adults aged 16+ (56% in men, 61% in women) (98).

Depression

The true prevalence of depression is difficult to estimate, owing to a lack of large-scale longitudinal general population studies in the literature (99). An estimate cited by NICE is an average lifetime prevalence of 14.6% in high-income countries (100).

There are an estimated 23,257 cases of depression across all age groups in Bedford Borough (prevalence of 12.6%), as calculated by NHS AGEM CSU for the 2025 DPH report.

Data is also available nationally on the prevalence of depression in those aged 18 and over. The prevalence in Bedford Borough is estimated at 13.20% (95% CI 13.21-54%) which is in line with the England average but significantly below the average prevalence of all local authorities in the fourth least deprived decile (Table 20).

Table 20 Total depression cases (aged 18+) in 2022/23 and prevalence (including 95% confidence intervals) In Bedford Borough, all local authorities in the fourth least deprived decile and England. Source: Fingertips Public health profiles (94)

Area	Total depression cases (aged 18+) in 2022/23	Prevalence (95% confidence interval)
Bedford Borough	20,679	13.20% (13.21-13.54%)
Local authorities in the fourth least deprived decile	934,672	14.11% (14.08-14.13%)
England	6,618,681	13.25% (13.24-13.26%)

Traumatic brain injury

Headway – a charity promoting awareness of and support for those affected by brain injuries – collects information on acquired brain injury related hospital admissions in the UK (101). The most recent data, from 2019-2020 and expressed as the rate per 100,000 population shows a rate of 492 across Bedfordshire Hospitals NHS Foundation Trust (NHSFT), compared with 530 in the East of England and 534 across the UK.

Physical activity

The Active Lives Adult Survey (ALAS) is an annual survey conducted by Sport England which collects information on physical activity, along with other metrics (102). The data from 2022/23 on the percentage of physically inactive (i.e. doing less than 30 minutes of moderate exercise per week) adults aged 19 and above gives a figure of 13.82% (95% CI 10.81-17.16%) in Bedford Borough, significantly below the England average of 22.60% (95% CI 22.39-22.79%).

Smoking

Smoking prevalence can be estimated from the Annual Population Survey, conducted by the ONS (103). Data from the 2023 APS estimates the current smoking prevalence in adults (aged 18 and over) in Bedford Borough at 13.95% (95% CI 7.56-19.74%). This is above, but not significantly different from, the estimated prevalence across all local authorities in the fourth least deprived decile (10.30%, 95% CI 8.78-11.81%) and England (11.63%, 95% CI 11.28-11.97%).

Diabetes

GP practices are required to maintain a register of patients living with diabetes as part of the Quality and Outcome Framework (QOF), which can be used to provide an estimate of prevalence. The smallest available geographical area is at the BLMK ICB level, which has a diabetes prevalence of 8.3% (95% CI 8.2-8.4%) among people aged 17 and over, significantly above the England average of 7.7% (95% CI 7.6-7.7% to 1 decimal place) (94). The true prevalence will likely be higher, however, given approximately 1 in 5 people living with diabetes are undiagnosed (104).

There are an estimated 12,701 diabetes cases across all age groups in Bedford Borough (prevalence of 6.89%), as estimated by NHS AGEM CSU for the 2025 DPH report.

Hypertension

Similarly to diabetes, hypertension prevalence can be estimated using QOF data (94). The smallest geographical area for which data is available is the BLMK ICB level, which has a prevalence of hypertension 13.7% (95% CI 13.6-13.8%) in people aged 17 and over, significantly below the England average of 14.8% (95% CI 14.8-14.8% to 1 decimal place). However, a BLMK long-term conditions Joint Strategic Needs Assessment estimated that in 2019/20, approximately one in three cases of hypertension are undiagnosed.

There are an estimated 30,386 cases of hypertension across all age groups in Bedford Borough (prevalence of 16.47%), as estimated by NHS AGEM CSU for the 2025 DPH report.

Improving the management of hypertension is a key priority for BLMK Integrated Care System (ICS). This is in the context of having the second poorest performance for hypertension management of any ICS in England in 2024 (105), with 62.4% of people with hypertension treated to target (ambition of 80%).

Obesity

The number of adults living with obesity (BMI 30 or above) is reported under QOF by GP practices in England (Table 21). In Bedford Borough, there are an estimated 19,985 people living with obesity in 2023/24, which equates to 12.63% (95% CI 12.47-12.79%). This figure is lower than the average across all local authorities in the fourth least deprived decile but in line with the England average of

12.80% (95% CI 12.79-12.81%). These figures are lower than national estimates produced from ALAS or HSE, which estimates the prevalence of people living with obesity at 25-30% (102,106).

Table 21 Total numbers of adults (aged 18+) living with obesity in 2023/24 with prevalence (including 95% confidence intervals) In Bedford Borough, all local authorities in the fourth least deprived decile and England. Source: Fingertips Public health profiles (94)

Area	Number of adults living with obesity	Percentage of all adults (95% confidence intervals)
Bedford Borough	19,985	12.63 (12.47-12.79)
Local authorities in the fourth least deprived decile	789,651	13.13 (13.11-13.16)
England	6,491,279	12.80 (12.79-12.81)

The prevalence of adults living with overweight including obesity (i.e. BMI 25 or above) is recorded by the ALAS. The estimated prevalence in Bedford Borough in 2022/23 was 62.07% (95% CI 57.32-66.83%), similar to the England average of 63.95% (63.70-64.20%). This illustrates the large proportion of the local population who are living with overweight but not yet living with obesity, regardless of the obesity estimate taken above.

Excessive alcohol consumption

While it only captures the extreme end of excessive alcohol consumption, admission episodes for alcohol-specific conditions can be seen as representative of the wider picture and be used as a tool to compare different areas. In 2022/23 there were 819 admissions for alcohol-specific conditions in Bedford Borough, giving a directly standardised rate per 100,000 population of 462 (95% CI 431-495, Table 22). This rate is significantly below both that across all local authorities in the fourth least deprived decile (517, 95% CI 512-522) and England (581, 95% CI 579-583).

Table 22 Total number of admission episodes for alcohol-specific conditions in 2022/23 and directly standardised rates per 100,000 population (including 95% confidence intervals) in Bedford Borough, all local authorities in the fourth least deprived decile and England. Source: Fingertips Public health profiles (94)

Area	Admission episodes for alcohol-specific conditions in 2022/23	Directly standardised rate per 100,000 population (95% confidence intervals)
Bedford Borough	819	462 (431-495)
Local authorities in the fourth least deprived decile	40442	517 (512-522)
England	320082	581 (579-583)

Late life (aged over 65 years)

Social isolation

An ONS public opinions and social trends survey, running across all of Great Britain from 13 December 2023 to 1 January 2024, found 27% of adults reported feeling lonely always, often or some of the time (107).

Household composition data from the 2021 Census can be used as a proxy measure of social isolation, given living alone is associated with reporting loneliness, although not the sole risk factor (90,108). In Bedford Borough, there were 21,448 one-person households in 2021, making up 28.62%

of all households. This compares to the regional East of England average of 28.90% and the England average of 30.09%.

Air pollution

Population-weighted annual average concentrations of fine particulate matter (PM2.5), a measure of air pollution, within England are provided by the Department for Environment, Food and Rural Affairs (94). The concentration in Bedford Borough is 8.29, which compares to an average of 7.49 across all local authorities in the fourth least deprived decile and an England average of 7.79.

Untreated vision loss

Estimating the number of people who have untreated vision loss is hard to estimate, but figures on the total number of people with visual impairment (treated or untreated) can provide an insight into this burden (109).

As of 2022-23, 650 people were registered blind in Bedford Borough, approximately 3 in every 1,000 based on 2023 population estimates. This compares to 4 in every 1,000 in the East of England and 5 in every 1,000 in England as a whole, also using 2023 population estimates.

Summary of the local prevalence of key risk factors for dementia

Table 23 outlines how the prevalence or presence of the key risk factors for dementia discussed above compare to the national (England where possible) average. It should be noted that, while a useful comparator, the national average does not indicate the most desirable outcome. It is important to note that differences may also indicate differences in diagnosis rates or measurement in Bedford Borough, rather than differences in the true prevalence or presence of a risk factor.

Table 23 Summary of the key risk factors for dementia in Bedford Borough relative to national averages

Risk factor	Bedford Borough relative to national average	
Less education (proportion of young people NEET)	Significantly lower than England average	🙂
Hearing loss	Local estimates based on national prevalence rates	NA
High cholesterol	Local estimates based on national prevalence rates	NA
Depression	Similar to the England average	😐
TBI incidence	Acquired brain injuries are lower than the UK average	Significance level unavailable
Physical inactivity	Significantly lower than the England average	🙂
Smoking	Higher than England average but not significantly different	😐
Diabetes	Regional (BLMK) prevalence significantly higher than England average	☹
Hypertension	Regional (BLMK) prevalence significantly lower than England average	🙂
Obesity	Similar to the England average	😐
Excessive alcohol consumption	Significantly lower than England average	🙂
Social isolation	Local estimates based on national prevalence rates	NA
Air pollution	Higher than the England average	Significance level unavailable
Untreated visual loss	Local estimates based on national prevalence rates	NA

Key:

🙂 **Significantly better than the national average**

😐 **Not significantly different to the national average**

☹ **Significantly worse than the national average**

Section 4 Describing Current Services

This section details some of the local services available in Bedford Borough, including health services, social services and other support services for people living with dementia and their carers.

Strategic overview

The 2016 Dementia HNA described a Dementia Stakeholder Group in Bedford Borough, whose members included representatives from BBC, Bedfordshire Clinical Commissioning Group (BCCG - now replaced by BLMK ICB), Bedford Hospital Trust (now part of Bedfordshire Hospitals NHSFT), Carers in Bedfordshire, Stroke Association, POhWER, Alzheimer's Society, South Essex Partnership University NHSFT, Dementia Friend Champions, Tibbs Dementia Foundation and St Andrews Care Home.

Dementia Operational Group

The Dementia Stakeholder Group has been replaced by the analogous Dementia Operational Group (DOG). The DOG brings together operational colleagues from across Bedford Borough and Central Bedfordshire quarterly and aims to work together and resolve issues at a local level. Membership includes representatives from:

- BLMK ICB (Commissioning Managers, GP Clinical Lead, Place-based dementia lead)
- Senior Commissioning Officer, Strategic Commissioning and Procurement (Adults), BBC
- Senior Strategic Commissioning Officer, Commissioning, Adult Social Care, Central Bedfordshire Council (CBC)
- East London NHSFT (ELFT)
    - Memory Assessment Service (MAS) (Operational Manager)
    - Dementia Intensive Support Service (DISS) and Bedfordshire Older People’s Crisis Resolution Home Treatment Team (Operational and Team Manager)
    - Learning Disability Service (Clinical Nurse Manager)
- Dementia UK (Admiral Nurse, Central Bedfordshire)
- Bedfordshire Hospitals NHSFT (Dementia Nurse Specialists)
- Public Health shared service for Bedford Borough, Central Bedfordshire and Milton Keynes (Public Health Manager and Public Health Consultant)
- Tibbs Dementia Foundation
- Carers in Bedfordshire
- Alzheimer’s Society
- Bedfordshire Care Group (Care Home Representatives)
- Bedfordshire Fire and Rescue Service
- Bedfordshire Police

BLMK Dementia Strategic Group

The BLMK Dementia Strategic Group meets monthly and has responsibilities regarding national targets and system-wide issues across the footprint of the ICB, as well as financial oversight. This group is specifically tasked with supporting efforts to ensure the national ambition of having estimated diagnosis rates of two thirds (67%) or higher is met across BLMK. Membership includes the following, although other members may be invited to relevant meetings by exception:

- BLMK ICB
    - Commissioning Manager
    - GP Clinical Lead
    - GP Frailty Lead
    - Place-based dementia lead
    - Quality Lead
- Programme manager for mental health, BLMK ICS
- ELFT and Central and North West London NHSFT (CNWL) MAS
    - Operational Manager
    - Clinical Lead
- Healthcare Public Health Consultant, Public Health Shared Service for Bedford Borough, Central Bedfordshire and Milton Keynes
- Representative from Luton Borough Council

The BLMK ICB Dementia Strategic Group reports directly into the BLMK ICS Mental Health, Learning Disabilities and Autism Delivery Group.

A summary of the groups described and reporting lines is illustrated in Figure 10.

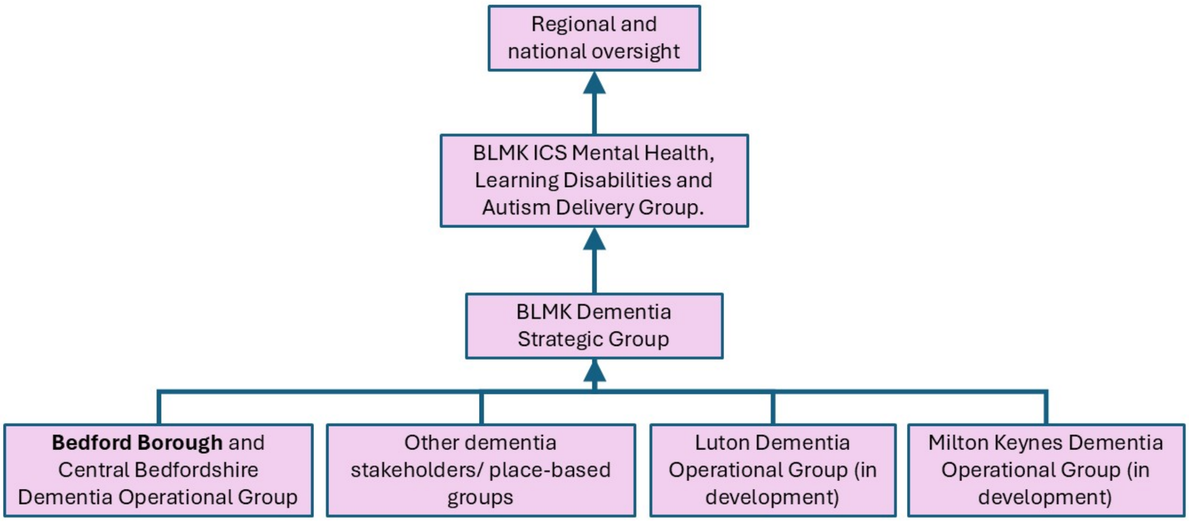

Figure 10 Strategic overview of dementia care in Bedford Borough

Primary care

GPs, often described as the ‘gatekeepers’ to secondary care, are the first port of call for many experiencing the first signs and symptoms of dementia. Initial screening assessments will take place before a referral to the MAS to confirm a diagnosis of dementia. GPs do not generally make diagnoses themselves, as per NICE guidance.

Ongoing clinical management following a diagnosis of dementia is also generally the responsibility of the GP, including liaising with secondary care and social care as appropriate.

Management of dementia in primary care is measured by two frameworks: the QOF and the Public Health Outcomes Framework and the relevant indicators are detailed in Table 24.

Providers of primary care also include pharmacies and dentists, and many staff are employed in GP practices in addition to GPs. They should also be considered in any recommendations relating to primary care.

Table 24 Measures of Dementia Care in Primary Care

Quality and Outcomes Framework (QOF)			**Public Health Outcomes Framework (PHOF)**	
Records	DEM001	The contractor establishes and maintains a register of patients diagnosed with dementia	E15	Estimated dementia diagnosis rate (aged 65 and older)
Ongoing management	DEM004	The percentage of patients diagnosed with dementia whose care plan has been reviewed in a face-to-face review in the preceding 12 months (achievement threshold: 35-70%)		

Secondary care

Memory assessment service

The Bedfordshire MAS operates across Bedford, Mid Bedfordshire and South Bedfordshire (including Luton) with facilities in Clapham, Dunstable and Biggleswade respectively. The service is provided by ELFT. As of September 2024, clinical staff included consultant psychiatrists, resident doctors, specialist dementia nurses, advanced clinical practitioners, psychologists and occupational therapists. Patients are not able to self-refer, but referrals from any health and social care professional will be considered.

The service aims to meet the needs of people who are concerned they may have a significant memory problem. The MAS is primarily engaged in assessing patients and making a diagnosis of dementia if appropriate. Findings are then reported to a patient’s GP and advice is given on further treatment and support. Where appropriate, dementia medication is prescribed, and patients are reviewed in prescription clinics before being discharged to the care of the GP on a shared care protocol once a stable dose has been reached.

Following diagnosis, the MAS can offer information, advice and support where appropriate. Monthly ‘Moving Forward’ sessions, which are held in person and alternate between Clapham and Biggleswade, aim to help PLWD and their carers understand and navigate the post-diagnostic support landscape. Attendees include, but are not limited to, representatives from Carers in Bedfordshire, Tibbs Dementia Foundation, AgeUK and Bedfordshire Fire and Rescue Service.

The MAS sees people with mild learning disabilities, while those with moderate or severe learning disabilities are seen by the specialist learning disability service.

DiADeM project

The MAS led an 18-month pilot of the Diagnosing Advanced Dementia Mandate (DiaDeM) in care homes project from November 2022 to May 2024. A team, led by psychologists, diagnosed PLWD by performing assessments in care home settings, where dementia prevalence is higher but many people live without formal diagnoses. All 38 care home residents who were assessed received a diagnosis.

Hospital inpatient services for people living with dementia

Bedford Borough is served by the Bedfordshire Hospitals NHSFT, which incorporates Bedford Hospital and Luton & Dunstable University Hospital. Dementia services have formally been in place since 2013, and there are several processes in place aiming to improve the care of PLWD.

Bedfordshire Hospitals NHSFT takes part in the Butterfly scheme which aims to improve the awareness of PLWD in hospitals, enabling them to access additional support. Hospital staff, friends and family are, with consent, encouraged to place butterfly stickers on the patient notes of PLWD. The patient’s electronic records are also updated, which means dementia specialist nurses are alerted in the current admission and also if the patient is readmitted in the future.

The trust employs specialist dementia nurses, who can respond to requests to review patients as well as visiting PLWD proactively. Dementia nurses make clinical assessments but are also involved in discharge planning, safeguarding processes and supporting carers.

More widely, all staff receive Tier 1 dementia training, with Tier 2 training targeted at those who have regular contact with PLWD. Patients living with dementia also have standardised care plans which involve enhanced monitoring.

Local support for people living with dementia and their carers

While primary and secondary care operate at reasonably defined time periods in the dementia journey, there are numerous services which offer support for those living with dementia, and their carers, from before diagnosis to the end of life. Local support services will be described in this section.

Dementia-specific services

Tibbs Dementia Foundation

Tibbs Dementia Foundation, formed in 2013 and granted charitable status in 2016, aims to enrich the lives of individuals living with dementia and their carers, through a range of groups and activities offered in face-to-face and online settings. These include those aimed at people experiencing mild memory difficulties to supporting bereaved carers. The full range of activities can be found in Table 25. These occur across Bedfordshire and if people wish to attend activities in Central Bedfordshire they are able to.

People can access Tibbs by making enquiries themselves or through referrals from others (often those working in health and social care). Tibbs then have conversations with the individual and/or their carer to identify how they can best be supported.

As of November 2024, Tibbs had approximately 75 volunteers and 9 full-time staff members, with many volunteers having used Tibbs services in the past. The service is funded through a contract to deliver dementia post-diagnostic support services jointly commissioned by BBC, CBC and BLMK ICB;

along with charitable grants and community fundraising. People who attend sessions are also encouraged to make small contributions if they are able.

Table 25 Tibbs Dementia Foundation Activities in Bedford Borough

Tibbs Dementia Foundation Activities in Bedford Borough	
Support 4 Memory	4 sessions designed to support people with recent dementia or cognitive impairment diagnosis and/or family and carers.
Cognitive Stimulation and Encompass Carers Group	14-week small structured sessions for people with early-stage dementia (or cognitive impairment). The carers Encompass group offers a safe space to share experience and information and runs alongside the Cognitive Stimulation Therapy session.
Activitea and Encompass Carers Group	Weekly semi-structured activity groups specifically for people with mid or later-stage dementia. Concurrent carers Encompass group.
Music 4 Memory	Groups facilitated by Music Therapists for all people living with dementia (or cognitive impairment) and/or their carer's.
The Big Sing	A chance for the Tibbs community across Bedfordshire to enjoy song, poetry, laughter and friendship every Saturday.
Challenges 4 Memory	Physically stimulating activities for people living with dementia (or cognitive impairment) and/or family carers, supervised by a qualified instructor. Includes walking football, indoor bowls and outdoor bowls in the summer, circuit training and a walking group. Online sessions include yoga.
Young onset group	A focused group to support people with a diagnosis of YOD (a diagnosis made under the age 65) and their carers/ families.
Still Caring Group: Bereavement Group and New Horizons	A group for those supporting a loved one in residential care and those who have lost a loved one. The bereavement group supports those living through loss after the death of a loved one. New Horizons is a group for those starting to look to the future.
Kempston drop-in	A weekly social group for people living with dementia or cognitive impairment to enjoy a relaxing afternoon with or without their carer or partner.
Beer and Banter	A fortnightly social group offering opportunities for men with dementia to meet without their care partner, to relax, chat and play board games together.
Lewy Body Group	A focused group to support people with a diagnosis of Lewy Body Dementia and their carers/ families.
Clear voices group	Discussion group for people living with dementia (or cognitive impairment) without carers.
Wellbeing workshops	Occasional workshops focusing on aspects of wellbeing, to build greater awareness and understanding of healthy lifestyle choices.
Current affairs	Forum for members of the Tibbs community to discuss goings on in the world.
Poetry	Group aimed at members of the Tibbs community with an interest in poetry.

Carers in Bedfordshire

Carers in Bedfordshire (CiB), formed in 2004, is a charity dedicated to supporting carers such that they can remain in a caring role for as long as they choose. This includes those caring for PLWD. People can self-refer into CiB but the organisation also receives referrals from other sources including Tibbs Dementia Foundation and NHS services.

CiB provide support to PLWD in two ways. The first is under the Carers Contract, which is commissioned by BBC and CBC to provide support for carers (whether this is related to dementia or not). The second is through the Memory Navigation Service, which is specifically commissioned by the aforementioned local authorities, along with the BLMK ICB, as a dementia-specific service.

As part of the Carers Contract, all carers are triaged through the registration service, with those categorised as highest need receiving help within 14 days. People can receive dementia information, advice and access a support worker. CiB also run a dementia befriending scheme, where volunteer carers support PLWD with regular social contact.

The Memory Navigation Service is provided by CiB staff but operates as a separate service. Unlike many of the other services, it is for carers and people experiencing memory difficulties. People are supported via telephone, email and also through an 'Emma Chatbot' on the Memory in Beds website. The aim of the service is to support people practically and emotionally with information on financial and legal assistance, physical health and wellbeing. There was a vacant Dementia Nurse post as of October 2024, who had previously been able to give clinical advice to PLWD and their carers. The service can also refer directly into Tibbs.

In Bedford Borough, CiB are commissioned by Bedford Borough Council to deliver a Carers Hub within Bedford Hospital. This service is co-located in the Patient Experience Hub alongside the Patient Advice and Liaison Service (PALS). The 'Hub' can support carers, whether they are visiting the hospital for themselves or their cared for person. The Hub also conducts regular ward visits, is involved in staff induction training and supports discharge planning.

A summary of activities and support groups provided by CiB, as part of the Carers Contract and Memory Navigation Service, is shown in Table 26. Similarly to with Tibbs Dementia Foundation, some activities take place outside of Bedford Borough which people are still able to attend should they wish to.

Table 26 Carers in Bedfordshire Activities in Bedford Borough

Carers in Bedfordshire Activities in Bedford Borough	
Dementia memory gateway	Monthly online meetings hosted by the Memory Navigation Service providing carers and PLWD with key information and advice on support available.
Dementia social	Monthly coffee catch-up and general discussion for carers and their loved ones living with dementia. Alternates between locations across Bedfordshire.
Dementia training	Sessions, commonly facilitated by external organisations, aimed at equipping carers with tools and information they can use when looking after a PLWD.
Carers in Bedfordshire Hubs	Monthly hubs in Bedford, Biggleswade and Dunstable and Marston Moretaine designed to give carers the chance to talk to support workers, share experiences with other carers and take a break from their caring role.
Carers drop-ins	Weekly social event for carers and former carers at Carers in Bedfordshire office (Bedford).
Former carers social group	Monthly meal for former carers in Henlow.
Carers choir	Weekly choir practice for carers to enjoy the benefits of singing in a group.
Online social support group	Opportunity to talk to support worker for those unable to attend in-person events.
Walking group	Monthly walking group based in Leighton Buzzard.

Dementia Intensive Support Service

The DISS operates across Bedford Borough and Central Bedfordshire, seven days a week from 9am-8pm. The primary aims of the service are to prevent unnecessary hospital or care home admissions and to help people live well with dementia. There were 25 staff members as of September 2024, which included consultant physicians, nurses (including nurse prescribers), support workers, social workers and occupational therapists.

DISS was initially developed in response to the cost of providing one-to-one care to PLWD in care homes. It was hypothesised this need could be reduced by optimising pharmacological and non-pharmacological management of dementia. The service has since expanded such that it now sees people in their own homes.

People need to have a diagnosis of dementia to access the service, and common reasons the DISS team are called include depression, agitation or aggression. All patients are seen within 24-48 hours of referral. A member of the DISS team will make an assessment and suggest a management plan, as well as giving advice on how to manage behaviours. Additional support is given to carers, with advice on accessing other services and referrals made where appropriate.

The DISS team also participate in community outreach and give training in care homes and other settings about caring for PLWD.

Other services in the community supporting people living with dementia

There are several services operating in Bedford Borough which, although not specifically designed to support those living with dementia and their carers, do interact with these groups as part of their day-to-day work. Several are listed below, which were raised during discussion with stakeholders, but there are many other community organisations who will support PLWD which are not mentioned here.

Bedford Older People's Community Mental Health Team

PLWD may require specialist mental health support in the community for:

- Assessment
- Care planning, coordination and monitoring
- Domiciliary support
- Occupational therapy
- Rehabilitation

Older People's Community Mental Health Teams (OPCMHT) are provided by ELFT in Bedford Borough. These are multi-disciplinary, multi-agency assessment teams for adults over the age of 65 who require specialist mental health services. People under the age of 65 living with YOD can also be cared for by this team. Staff employed by the service include community psychiatric nurses, occupational therapists, psychologists, approved social workers, support workers and psychiatrists.

Social care

The Bedford Borough social care team supports PLWD and their carers in several different ways. Before these needs can be met, eligibility of either the carer or cared for is determined by a needs assessment.

Financial assistance

Various financial benefits can be claimed, for either a carer or a person living with dementia. These include the attendance allowance, carer's allowance, carer's credit, carer grants, personal independence payments and universal credit. Eligibility for these varies according to age, disability and other factors.

Day Centres

Day centres are available in Bedford Borough for older people including those living with dementia. These provide respite for the people and their carers, and the centres aim to prevent or delay hospital and/or care home admissions.

Domiciliary care

Domiciliary or home care is available to help a PLWD with washing and getting dressed, as well as other tasks.

Respite care

Respite care can be accessed to enable a carer to take a break from their caring role.

Sheltered accommodation

Sheltered housing is designed specifically to meet the needs of older people, with low level support or assistance available to support people to live independently.

BBC also provide two 'extra care' sheltered housing facilities designed for residents with a higher degree of need. These are Dame Alice Court and Tavistock Court, which have both been rated as 'Good' in their most recent CQC inspections.

Care homes

Care homes include residential and nursing homes. Residential care homes provide assistance with personal care, meals and going to the toilet while nursing homes offer 24-hour care by trained nursing staff. BBC operate several care homes.

Bedfordshire Police

Bedfordshire police follow the Herbert Protocol, a safeguarding initiative to identify vulnerable individuals, particularly those with dementia, who go missing. Carers or relatives can pre-fill a form with essential information such as medical history, habits, and a recent photo, which can be quickly accessed in an emergency.

Bedfordshire Fire and Rescue Service

The Bedfordshire Fire and Rescue Service operates across Bedford Borough, Central Bedfordshire and Luton. The service conducts Home Fire Safety Visits which anyone can request, but priority groups include over 65s, people living with a disability and those living on their own. When visiting someone living with dementia, advice is tailored appropriately, and the service aims to ensure a carer is present. A previous scheme, 'Dementia Safety First', provided annual re-visits for PLWD but this is no longer funded.

Specialist Services for People with a Learning Disability

The Specialist Services for People with a Learning Disability (SPLD) operates across Bedfordshire and Luton and is provided by ELFT.

SPLD do memory screening for people living with Down’s Syndrome from age 30, and all other patients under their care from age 50. If there are concerns before these age thresholds, people can self-refer or be directed by their GPs or other healthcare professionals.

Screening and assessment are adapted so that they are appropriate for people living with a learning disability, and a multidisciplinary approach is taken to determine if someone should receive a diagnosis of dementia.

As of October 2024, there is no formal post-diagnostic pathway, however work is being conducted by SPLD to develop this in conjunction with relevant organisations.

HM Prison Bedford

Bedford prison is the sole prison in Bedfordshire and is a remand prison, meaning it holds people in detention before trial if bail is not deemed appropriate; and also if their sentence is 12 months or less. This means there is a relatively high turnover of prisoners.

Prisons have GPs attached to each facility, but when on remand one remains registered to the GP one used prior to entering the prison estate. As of December 2024, Luton Crown Court – which sees cases from Bedford Borough – was holding people on remand in HMP Peterborough. Therefore, the majority of the Bedford Prison population was in fact registered to GPs in Hertfordshire.

Healthcare within the prison is provided by Northamptonshire Healthcare NHSFT, and services include a GP who visits daily, psychiatrist twice weekly and mental health nurse provision. Care for dementia is included in the contract but it is not specified how this should be delivered. A Standard Operating Procedure is currently being developed for Bedford prison (as of December 2024), to allow prison healthcare professionals to assess and refer patients to the MAS. Prisoners also need escorts to healthcare appointments and each facility must be risk-assessed – the MAS has not yet been risk assessed, presenting additional challenges in the diagnostic pathway.

While in detention, prisoners receive social care needs assessments, which can facilitate additional assistance, for example getting dressed or installation of grab rails. This also informs safe destinations for release, which is important given that prisoners are unable to be detained any longer than their sentence duration.

National services

In addition to local services, there are several national services which have a presence in Bedford Borough or operate advice lines which can be accessed by residents. These include, but are not limited to:

- AgeUK (Bedfordshire)
- DementiaUK
- Alzheimer’s Society
- Young Dementia Network
- Rare Dementia Support
- Carers Trust
- MacIntyre Charity
- Carers UK
- Samaritans
- Rethink Mental Illness
- MIND
- SANE

Section 5 Stakeholder views

Summary of stakeholder views

Unmet need includes access to a timely diagnosis, as well as management and support following this.

Gaps in the treatment pathway include smooth transitions between services and access to new therapies and clinical trials.

A number of **hidden populations** were identified, including: people who live alone, those experiencing homelessness, traveller communities and those in prison.

Enablers of treatment included: joined-up services, the use of digital tools and co-production with service users.

Barriers to treatment included: services working in silos; a lack of awareness about dementia and available support; and services not being accessible to all.

Stakeholders provided many **suggestions for improvement** which included: a focus on living well with dementia; having a single point of access across the dementia pathway; and reviewing diagnostic processes.

Younger people living with dementia were identified as experiencing longer waits before diagnosis and having different care needs to others living with dementia.

Stakeholders suggested issues facing **people living with dementia from different ethnic backgrounds** included lower awareness of dementia, challenges accessing services and greater stigma associated with dementia.

Those living with dementia and a learning disability were identified as being at risk of falling between services, with work ongoing to address this.

Background and methodology

In August 2024, a stakeholder identification meeting was held with:

- Assistant DPH for Central Bedfordshire working across the shared public health service in Bedford Borough, Central Bedfordshire and Milton Keynes
- Senior Commissioning Officer, Strategic Commissioning and Procurement (Adults), BBC
- Senior Strategic Commissioning Officer, Commissioning, Adult Social Care, CBC

The stakeholders identified were approached to explain the HNA process and arrange stakeholder interviews. Stakeholders were also encouraged to suggest others who may be able to contribute, identifying any who may have been missed in the initial identification meeting. The people in post in the job roles described for stakeholders in the 2016 edition were also contacted, where the organisation remained involved in the delivery of dementia services. Many stakeholders worked across Bedford Borough and Central Bedfordshire. However, where issues were specific to Bedford Borough, stakeholders were encouraged to report this.

Face-to-face or virtual interviews were held with the following:

- Senior Commissioning Manager for Adult Mental Health, BLMK ICB
- GP and Frailty Lead, BLMK ICB
- Consultant Old Age Psychiatrist, Clinical Lead, MAS, ELFT
- Operational Manager, Pan Luton and Bedfordshire MAS, ELFT
- Lead Dementia Nurse Specialist, Bedfordshire Hospitals NHSFT
- Operational Manager, DISS and Bedfordshire Older People's Crisis Resolution Home Treatment Team
- Team Manager, DISS and Bedfordshire Older People's Crisis Resolution Home Treatment Team
- Chief Executive Officer, Tibbs Dementia Foundation
- Adult Carer Service Lead, Carers in Bedfordshire
- Clinical Nurse Manager, Learning Disability Service, ELFT

Stakeholder focus groups were also held with staff and volunteers from Tibbs Dementia Foundation in Bedford Borough.

The same set of eight questions, under which findings are presented, were asked to all stakeholders. These are the same questions asked in the 2016 dementia health needs assessment. By asking these again, it is hoped areas of change since the previous report can be charted more accurately.

Themes emerging from the interviews will now be presented.

1. What are the current unmet needs across the health and care system?

Four main themes emerged in response to this question: timely diagnosis, management and support following diagnosis, carers' needs and access to social care.

Timely diagnosis

There was general concern shared by many of the stakeholders that PLWD were not receiving their diagnosis quickly enough, for which several reasons were proposed.

Some stakeholders proposed this may be due to a lack of awareness from the general population regarding dementia as a condition, and the importance of receiving a diagnosis in terms of accessing support.

Some expressed a view that not enough referrals were being made to the MAS, with healthcare professionals falsely reassuring patients that becoming forgetful was a part of normal ageing or failing to listen to carers, friends and family who had more insight than the presenting patient.

Concerns were also expressed regarding delays following a referral to the MAS. Some knew of patients who had waited several weeks or months before an initial appointment, and even after being seen, completing the necessary procedures and scans can add further delays.

Management and support following diagnosis

Many stakeholders also expressed a view that, following diagnosis, management and support was not meeting the needs of PLWD.

This particularly related to those who need additional support but are not in crisis or in need of admission to hospital. The annual reviews conducted by GPs present an opportunity to monitor if PLWD require additional support, but many felt these were not being used as effectively as they could be. One stakeholder also felt there was insufficient monitoring of medication, and that in many instances some drugs were still being prescribed despite a poor risk-benefit profile.

Some stakeholders also felt, with regards to the later stages of dementia, that insufficient attention was paid to advanced care planning and palliative care relative to other terminal conditions. Advanced care planning involves discussions with the patient and their family to agree on how they would prefer to be treated. One example could be a PLWD having a preference to be treated at home in a familiar environment should they become unwell, rather than being admitted to hospital. However, one stakeholder observed people being readmitted to hospital in spite of initial discussions on previous admissions and advice on discharge to continue these in primary care. Failing to act in these cases may present missed opportunities to prevent hospital (re-)admissions.

Carers' needs

There was widespread acknowledgement that carers played a significant role in the care of someone living with dementia. Many stakeholders then spoke of how this population's needs were not being met. In some instances, people spoke of carers not being adequately involved in the care of someone living with dementia, depriving that person of a vital mouthpiece and an individual who has significant insight into the person's condition. Stakeholders also felt there was insufficient support for carers. This includes difficulties accessing financial assistance they are entitled to, but also education and training into how best to care for the person with dementia.

Access to social care

Access to social care was also frequently brought up as an unmet need by stakeholders. People were often said to have trouble finding out what support was available, and when they did attempt to access this, they found the required application forms complicated and cumbersome. Many turned to voluntary organisations for help filling out these forms. Some stakeholders suggested inequalities may arise, with only the more assertive and knowledgeable individuals accessing the appropriate support.

2. Where are the gaps in the treatment system?

Four key themes emerged regarding gaps in the current treatment system: transitions between service providers, making diagnoses outside of the MAS, existing services not being dementia friendly and access to new therapies and clinical trials.

Transitions between service providers

A common theme across almost all the interviews, wherever in the pathway the stakeholder operated, was of perceived gaps when leaving one service and entering the next. This may be at the point of referral from the GP to the memory clinic, where some stakeholders reported patients declining an appointment despite lacking insight into their condition. Also, when PLWD and their carer are discharged from the MAS and may feel lost and confused about where to turn to for post-diagnostic support. Stakeholders also reported gaps arising between secondary and primary care, for example on discharge from hospital.

Some stakeholders perceived these gaps as arising due to the involvement of many different providers along the dementia pathway. There is no uniform 'brand', and not all are provided under an NHS banner which may cause confusion for patients. Some also cited the lack of link workers, or similar, who can be with someone throughout the whole of their dementia journey and smooth out any gaps along the way.

Making diagnoses outside of MAS

Many stakeholders expressed frustration that diagnoses were not made outside the MAS. Very few hospital consultants make formal diagnoses, and GPs have been advised not to make diagnoses under normal circumstances. This places additional pressure on the MAS and can create a bottleneck if the service cannot keep up with demand. Consequences of this include an inability for symptomatic individuals to access services which require a diagnosis of dementia, until after a (possibly lengthy) wait to have this confirmed by the MAS.

Existing services not being dementia friendly

PLWD are often treated under the specialties of medicine for older people or psychiatry. Several stakeholders commented on aspects of care which work well for most patients in these specialties, but which have not been adapted appropriately for PLWD. This included the discharge to assess pathway, where people admitted to hospital have their care needs assessed in another facility, such as a care home, to both preserve hospital capacity and allow an accurate assessment of an individual's care needs. This may prove problematic for PLWD, however, where increased numbers of unfamiliar environments can worsen confusion and cause distress. The need for tailored wellbeing services was also discussed, with PLWD not always able to engage in traditional talking therapies, meaning alternatives must be considered.

Access to new therapies and clinical trials

Some stakeholders spoke of the changing horizons of dementia care with access to new therapies and interventions likely in the coming years. However, a view was expressed that there was a gap in Bedford Borough with regards to participation in clinical trials. One stakeholder described how people often had to travel out of area to other regions with larger, established research centres if they wanted to participate in these.

3. Who are the hidden populations and what are their risks?

The hidden populations in Bedford Borough as identified by stakeholders are shown in Table 27, along with risks specific to individuals in these groups. Although identified as hidden populations, PLWD who are either younger, from ethnic minority backgrounds or have a learning disability are not listed in the table as they are discussed in more detail in relation to specific questions. It is also important to note that despite being identified as 'hidden', this does not mean services are not making attempts to reach these populations. For example, Tibbs Dementia Foundation have from 2024 begun a concerted effort to ensure services are provided in rural communities. There are also services for many other groups identified which are discussed elsewhere in this HNA.

Table 27 Hidden populations of people living with dementia in Bedford Borough and associated risks, as identified by stakeholders

Population	Risk
People living in care homes	Many stakeholders commented on sub-optimal diagnosis of people in care homes living with dementia, with one stating ‘dementia is often acknowledged but not diagnosed’. Concerns were raised that, without a diagnosis, the care home population may not be able to access all the services they are entitled to.
People living with drug and/or alcohol-dependence	Those who live with drug and/or alcohol-dependence are an already vulnerable population and face increased risks of many health conditions. Stakeholders commented that, with regards to dementia, people living with alcohol-dependence faced increased risks of alcohol-related dementia. More generally, care providers can face challenges when assessing and engaging this population relative to other service users, due to increased risks of not attending appointments or presenting with challenging behaviour.
People who live alone	Many PLWD lack insight into their condition, therefore those who live alone without a strong support network may slowly deteriorate and only seek help when in a crisis. They may also face additional challenges when in the health and care system, with difficulties remembering when and where appointments are and less support with everyday tasks at home.
Digitally excluded	Many services have moved online or remote, with this change accelerated by the COVID-19 pandemic. While the general population have become more digitally literate some, particularly older people more at risk of dementia, increasingly struggle to access services. This is especially the case when forms are ‘online only’ (with no paper copies) or when appointments can only be booked via automated telephone ‘queues’.
Rural populations	People living in rural areas, particularly in North Bedfordshire, may face social isolation. This is particularly true if they lack the means of transport to travel to support groups.
People living with mild cognitive impairment	This population can face difficulty seeking support as they do not have a diagnosis of dementia but would benefit from many of the same services. People living with MCI may be reluctant to use ‘dementia’ services, even if they are eligible, as they do not recognise themselves as having the condition.
People living with rare dementia types	Some stakeholders commented that although people living with different dementia types have different needs, much of the standard advice is aimed at people living with AD with little-to-no tailoring of this to people living with other dementia types.
People experiencing homelessness	People experiencing homelessness may face additional challenges accessing healthcare and support services relative to the general population. Additional support is likely required to raise awareness of dementia in this community and to help them access appropriate services.
Traveller communities	The traveller communities in Bedford Borough are known to have lower contact with health and social care services which could lead to lower diagnosis rates and reduced access to support services.
Frail population	PLWD are often frail, given it is primarily a disease of older age. If people are frail prior to developing dementia, this can impact on their ability to access services. If someone developing dementia also has a frail carer, this can increase care needs rapidly and quickly lead to a crisis.
People with pre-existing psychiatric conditions	If people develop dementia superimposed on pre-existing psychiatric conditions, this can lead to complex care needs which services are not generally set up for.

People being cared for by male carers	Some stakeholders commented that, particularly in post-diagnostic support services provided by the voluntary and charity sector, there was a noticeable gender imbalance. Most people attending support groups were males living with dementia accompanied by female carers, and as many of the volunteers were former service users, services were generally provided by women. There was a concern that male carers were finding it more difficult to find and access support.
People in prisons	Some stakeholders were concerned about PLWD in prisons, where people should have the same access to healthcare as in the community, but this is not always the case. The structured nature and regime of prison may also mask symptoms if people are not required to cognitively engage. Symptoms may also be misinterpreted by staff as laziness or not engaging if they are not aware of the possibility of cognitive decline. The loud environment of most prisons may also be overstimulating for people with moderate-severe dementia. Prisons may also have difficulty finding appropriate release destinations, with some care homes refusing to take former offenders.

4. What are the…

a. …Enablers to treatment or management in the dementia pathway?

When discussing the enablers of treatment or management in the dementia pathway with stakeholders, four key themes emerged: development of new services, joined-up care, digital tools and co-production.

Development of new services

Many of the stakeholders interviewed had been involved in dementia care over several years. They often commented on how the introduction of services to address previously identified needs, or to fill gaps in the dementia pathway, had improved care for patients.

Examples include the Hospital at Home and DISS service, which help to prevent hospital admissions. Also, the formal commissioning of services in the voluntary sector such as Tibbs and Carers in Bedfordshire, whose work was widely praised by many of the stakeholders.

Additionally, stakeholders identified areas where existing services had been expanded to fulfil needs through recruitment of new roles or upskilling existing staff. For example, in the MAS, staff can now perform ECGs and blood tests in-house; and nurse prescribers have reduced the burden on doctors.

Joined-up care

Although hard to define, stakeholders frequently cited ‘joined-up care’ as an enabler of managing PLWD.

Often this involved good links with other services, both within and outside of the dementia pathway. For example, the specialist dementia nurses at Bedfordshire Hospitals NHSFT have strong links with DISS and the MAS, but also the inpatient psychiatric liaison team who are key partners when medication needs to be prescribed, or alternative diagnoses considered.

Sharing of information was also cited as important in delivering joined-up care. For example, in recent years the MAS has been able to access GP Summary Care Records and investigation results. This improves the triaging process for the MAS, and the accepting of referrals which may previously have been rejected due to a lack of detail.

Digital tools

Several stakeholders working in service delivery cited the introduction of digital tools as enabling them to provide more, higher quality care. Examples included the electronic recording of notes and patient observations by the DISS team, and electronic prescribing by the MAS.

Co-production

Overall, stakeholders valued co-production in developing new services. They felt involving PLWD and other relevant partners improved the appropriateness of care and allowed it to better meet the needs of the population. It was cited that many in the voluntary sector regularly took user feedback into account when deciding on what services to deliver. This allowed them to be flexible and meant they could readily adapt to change.

b. …Barriers to treatment or management in the dementia pathway?

In terms of barriers, four primary themes were identified: insufficient resource; services working in silo; lack of awareness of dementia care and support; and services not being accessible.

Insufficient resource

Several stakeholders expressed frustration at a lack of human resource, particularly in services where demand appeared to outstrip supply and increasing staff numbers may allow more patients to be seen. This also applied to a lack of funding for potentially effective medication. Stakeholders reported patients querying eligibility for new treatments they had read about in the media and that they were often disappointed when they learned they were not funded.

Services working in silo

Although appreciating areas where care was joined-up as described above, many stakeholders also felt services working in silo was a barrier to managing the care of PLWD.

Stakeholders felt having several different service providers along the dementia journey, and geographic variability over what is provided where, makes it confusing for patients and carers. This also applies to the health or social care professional attempting to provide accurate information.

Some also expressed frustration about uncoordinated campaigns. Although national campaigns or increased media coverage raising awareness of dementia are welcome, this sometimes led to surges in demand which services were ill-equipped for.

Lack of awareness of dementia care and support

More generally, many stakeholders felt that the wider population were not aware or adequately informed about dementia care and support on offer. This may lead to people not seeing any value in receiving a diagnosis if they are unaware of the treatment and support they can access. Some also commented on the lack of visibility of services, for example in the waiting rooms of clinical buildings there was often reported to be no or inaccurate information on post-diagnostic support services.

Services not being accessible

If people are to use services, it is important that they are accessible, and some stakeholders raised concerns as to if this was always the case.

Some services lack car parking, others have poor public transport connections and service users can sometimes have difficulty entering buildings. Transport is a key issue for PLWD, as they often lose the ability to drive as their condition worsens. Some also commented on how common forms of transport, such as bus or taxi, can be inappropriate if there is no one available to escort the PLWD from the vehicle to the venue.

5. What improvements can be made to future service provision?

Many suggestions were made from stakeholders regarding potential improvements to dementia services in Bedford Borough. Broadly, these fell into five themes: A shared dementia care pathway with a single point of access; reviewing diagnostic processes; a focus on living well with dementia, support for carers; and making services accessible. Improvements related to younger people, ethnic minority communities and people living with a learning disability will be discussed in the relevant sections.

Shared dementia care pathway with single point of access

Stakeholders frequently commented on how aligning all services under a single pathway could not only improve relationships between organisations, but also facilitate better care for service users. Several comments were also made on the importance of a single point of access, or link workers, who can help PLWD and their carers navigate the dementia landscape. People felt this could help to address some of the current challenges of services working in silos and confusion regarding how and where to access services.

Specific examples were also given by stakeholders with regards to this joined-up approach. One mentioned the possibility of increasing digitalisation of services facilitating shared records. Clearly, information governance hurdles would need to be cleared but such a practice could greatly improve the integration of services. A key shift would be a move from the current consent-based system of data-sharing to an ‘opt-out’ model whereby everyone with a diagnosis of dementia could be followed up to ensure care needs are met. The annual dementia review, which GPs are required to do under QOF agreements, was also mentioned by stakeholders as an opportunity to adopt a multi-agency approach and greatly improve its usefulness for services, PLWD and their carers.

Reviewing diagnostic processes

Diagnosing dementia was raised by stakeholders in relation to many of the other questions, and several suggested a review of current diagnostic processes to find areas for improvement.

Some stakeholders questioned whether the current process allowed the maximum number of patients to be seen in the shortest time possible. A model where one consultant supervises several staff seeing patients, with investigations such as ECGs and blood tests done on the same day, could speed up the assessment process from several weeks to one day in some cases. Waiting for scan results was cited as a possible area which could be streamlined, with proposed solutions including GPs ordering them at the time of referral or a ‘fast-track’ agreement with radiology departments. A need for improved services for people requiring specialist tests out of area, such as genetic testing or cerebrospinal fluid investigations, was also cited. These often involve long waits, which impact the timeliness of diagnosis.

Several suggestions were made as to how to safely make diagnoses outside of the MAS and work is ongoing at the time of writing this HNA to assess how these may be implemented. These included GPs with a special interest in dementia doing sessions at the MAS, expanding the coverage of the DiADeM tool and diagnosing PLWD in care homes at their residence (rather than inviting them individually to the MAS).

Pre-diagnostic counselling was cited by one stakeholder as one aspect of the diagnostic process which is often overlooked. Some patients they had encountered had cited suicidal ideation in relation to receiving a dementia diagnosis. Integrating counselling into services could help people when they receive diagnoses and prevent poor outcomes.

A focus on living well with dementia

Many stakeholders emphasised the importance of focussing on living well with dementia, with concerns that current services were too often oriented towards what may go wrong.

Social activities involving fun and bringing enjoyment, thereby attracting others to attend, were cited as one example. Many of these are already facilitated by post-diagnostic support services, including Tibbs, Carers in Bedfordshire and Day Centres. Places where these activities take place can be community hubs and become much more than just a space for PLWD and their carers to come together. An opportunity to emphasise wellbeing was also linked to the concept of living well with dementia, with a diagnosis perhaps offering a chance to give a general refresher of general wellbeing advice.

Promoting living well with dementia was said by some stakeholders to require education of healthcare professionals and staff working in dementia services, as well as wider awareness in the general population. This may therefore require specific communication strategies to raise awareness of how a dementia diagnosis can bring many benefits and improve quality of life.

Support for carers

Adequate support for carers was mentioned by almost all stakeholders as essential to successful dementia care, but also a key area for improvement.

Suggestions included easier access to respite and wider support for carers; live-in carers as alternatives to care homes – where PLWD are uprooted to an unfamiliar environment; and improved communication. Communicating well includes acknowledgement that a carer is largely responsible for the PLWD attending appointments and engaging with healthcare. As such, there should be mechanisms in place allowing carers to be more closely involved in their loved-one’s care, from appointments to prescriptions.

Making services accessible

Some stakeholders queried the accessibility of current services and acknowledged that, although they meet the needs of many, perhaps improvements could be made to ensure people are not discouraged from seeking help.

Examples include improved car parking facilities, ensuring facilities can be reached by public transport where possible, offering face-to-face appointments for PLWD and providing an option for appointments outside of working hours. Accessibility will be further discussed in relation to the remaining questions.

6. What is your knowledge of services or particular issues facing…

a. …Younger people living with dementia?

Stakeholders were specifically asked about their knowledge of services or particular issues facing groups who are known to experience inequalities in relation to dementia. Four primary themes were identified regarding younger people (i.e. those under 65 at the time of diagnosis): Longer waits before diagnosis; different care needs to the general dementia population; an increased financial burden; and falling into gaps between services.

Longer waits before diagnosis

Stakeholders acknowledged that younger PLWD often experienced longer waits before receiving a diagnosis. Much of this is for good reason, with younger people typically requiring more specialised assessments due to other more common conditions for this age group needing to be excluded. However, some stakeholders felt the wait was excessive in some cases and more could be done.

Different care needs to the general dementia population

Most PLWD were identified by stakeholders as being much older than the arbitrary age of 65, usually in their 70s or 80s, and therefore those who were classified as ‘younger’ often had very different care needs.

At diagnosis, younger PLWD may still be working which stakeholders commented led to trouble accessing services during working hours and higher ‘Did Not Attend’ (DNA) figures versus older people. This also applies to their carer, who may be a person’s source of transport or want to attend support services themselves.

Stakeholders also commented that someone in their 50s, for example, may have little in common with people 20-40 years their senior who they may encounter at support groups. Younger people were also often more mobile, and likely to enjoy activities involving more physical activity.

An increased financial burden

Some stakeholders also commented that the financial burden on younger PLWD would likely be more significant than those in older age. This is due to the loss of earning potential if they are of working age, whilst still having to support children in many cases or having mortgages to pay. The carer’s earning ability may also be similarly affected. This financial pressure will be common to many chronic conditions in people of working age, but given dementia is seen as a disease of older age support services may be less well-equipped to support people.

Falling into gaps between services

Younger PLWD were sometimes perceived as ‘falling into gaps’ between services. As an example, younger PLWD can access the OPCMHT, but often access the general adult team first, especially if pre-diagnosis, who are less well set up to manage dementia. Some work is being done to address the gaps in current services, for example Tibbs have specific groups for younger people and have partnered with ELFT to deliver this.

Improvements

Suggestions for improvement in care for younger PLWD followed on from what has been discussed. An increased recognition of how this population's needs differ and strategies to address inequities were priorities. Many felt relatively simple actions, such as providing training for staff about how best to manage younger people, would be beneficial.

b. …People living with dementia from different ethnic backgrounds?

Bedford Borough is home to people from a diverse range of ethnic backgrounds, with approximately 36% self-identifying as belonging to an ethnic group other than White British in the most recent Census in 2021. This question sought to explore some of the challenges faced by this population, whilst recognising that there is significant variation between people from different backgrounds and cultures and this group cannot be treated as one. Five themes emerged amongst responses to this question centring around: awareness, accessibility, stigma, trust and culture. Suggestions for improvements were also made.

Awareness

A lack of awareness, both around dementia in general and support services, was cited as a particular issue in some communities. Several stakeholders, some of whom had been informed by outreach work, commented on how in some languages there was no recognised word which referred specifically to dementia. This may contribute to a lack of awareness and mean that some do not seek support when symptoms first appear. One stakeholder also commented on how this lack of awareness may work both ways, with feedback from an Afro-Caribbean community group that clinicians had been slow to acknowledge concerns regarding memory issues. The group attributed this to reduced signs of ageing in people of darker skin types and less awareness of dementia in people from these communities.

Accessibility

Even if awareness is addressed, some stakeholders questioned how accessible current dementia services are for people from different ethnic backgrounds.

Particular issues were described in relation to people who either did not speak English, or did so as a second language. Memory tests often involve written and visual components, which adds complexity for those who do not speak English. The MAS use the Rowland Universal Dementia Assessment Scale (RUDAS) which minimises the effects of cultural learning and language diversity, but screening and assessment may still be affected at other stages in the dementia pathway. Booking appointments for people with English as a second language often involves liaising with family members, and it was felt this increased the risk of DNAs. Services for translation were also described as being variable. While generally available in NHS services, those in the voluntary sector did not have the resource to support formal translation. Some services were able to utilise staff members who spoke the language of service-users but acknowledged they should not rely on this and ideally robust translation processes should be in place.

The cultural appropriateness of certain services was also raised. Stakeholders, particularly those delivering post-diagnostic support commented on how those accessing services were predominantly White British, and that it was rare to see people from other ethnic backgrounds. Suggestions were made that some activities may not hold universal appeal, for example the music therapy sessions primarily involving music aimed at a White British cohort. There may also be a reluctance from people of different religious backgrounds to attend sessions held in churches.

Stigma

Several stakeholders felt there was a stigma attached to dementia, and mental health more widely, which was greater in some ethnic minority communities. If such a stigma exists, this may reduce further the incentive to seek support from those who fear such a diagnosis will isolate them and their family.

Trust

Another factor which may affect how some people from different ethnic backgrounds are able access support for dementia is a lack of trust, either in western medicine and/or the NHS. Some of the stakeholders felt this was a barrier to providing care in certain communities. This trust, where present, was also described as being hard-earned and taking a long time to build. It often revolved around developing good relationships with community leaders, and a focus on wellbeing rather than the consequences of disease.

Culture

Some stakeholders also queried whether how and why people from different ethnic backgrounds accessed services was affected by cultural influences. Particular reference was made to multi-generational housing and a greater willingness to look after elders for longer in this setting. This often meant people's first presentation to health services was when crisis point had been reached. Others mentioned how they knew of some who had grown up abroad and chosen to return to their country of origin, either as they perceived a higher quality of care there or because their mother tongue language was better preserved.

Improvements

Several suggestions were made by stakeholders which could reduce inequalities faced by people from different ethnic backgrounds.

One was to continue and increase existing outreach work, to raise awareness of dementia as a disease and the support available. Places of worship, such as churches, gurdwaras and mosques represented cultural hubs and could be appropriate venues for such outreach work.

Stakeholders also expressed an interest in having 'Community Champions', who could facilitate links between services and underrepresented communities. They could become involved in co-production to ensure services meet the needs of people from all backgrounds and ensure people feel welcome when they attend support groups for the first time.

Living well with dementia was a general suggestion for improvement but was given particular weighting in relation to people from different ethnic backgrounds. In situations where there is no word for dementia or reduced awareness of it as a concept, having a focus on wellbeing may represent a route into these communities. Once relationships have been built, this may represent an opportune time to discuss memory loss.

The communities in Bedford Borough will continue to change and stakeholders were mindful that any new or developing communities from different ethnic backgrounds should be engaged to assess their needs.

c. …People living with dementia and a learning disability?

Not all stakeholders were familiar with the issues facing this group, but where comments were made, they primarily related to integration between learning disability and dementia support services; and the stigma attached to people living with learning disabilities in some communities. Some suggestions for improvement were also made.

Integration between learning disability and dementia support services

Stakeholders commented that most people living with a learning disability were looked after well by the SPLD team, with relatively minimal input from dementia care providers. The MAS does see people living with mild learning disabilities, and this group could face challenges if MAS staff do not feel confident caring for them. While the MAS does receive training sessions from the SPLD team, if these learnt tools are not used regularly they risk becoming deskilled. It was felt this siloed approach could also mean best practice not being shared and elements of work being duplicated. In the wider care system, for example in care homes and GP practices, it was felt awareness of the increased risk of dementia in people living with a learning disability was not always appreciated

Stigma attached to learning disabilities in some communities

Stigma was mentioned as an important issue facing people from different ethnic backgrounds living with dementia, and this was also cited in relation to those living with learning disabilities. If learning disabilities are also seen as a taboo subject in certain communities, this may make it doubly hard to engage.

Improvements

Suggested improvements included increased training for care providers to elevate awareness of raised dementia risk in PLWD and increase confidence when looking after this population. Ensuring that dementia services are inclusive, for example by having appropriate screening tools and information available in easy-read format, is also important.

Section 6 The views of people living with dementia and their carers

Summary of the views of people living with dementia and their carers

Several themes emerged from unstructured interviews with people living with dementia and their carers. These can be loosely categorised according to the prompts which were used to guide conversations:

Diagnosis – There was felt to be a lack of awareness of dementia in the general population which could delay diagnosis. This may be compounded if healthcare professionals struggled to provide people with the support they needed.

Knowledge about services – Many people attending post-diagnostic support services were not initially aware of the offer and commented that it was difficult to navigate all the support available.

Access to services – People living with dementia and their carers described difficulties accessing activity and support, sometimes encountering administrative barriers.

Support for the person living with dementia – The need for holistic care was discussed, as well as tailored support which appreciates the differences between forms of dementia. The annual dementia review was mentioned as a process which could be valuable with engagement from all involved.

Support for the carer – Carers discussed the demanding nature of supporting someone living with dementia. Sometimes this meant they struggled to find time to look after themselves, for example seeking treatment for their own health needs.

Quality of life both for the person with dementia and for the carer – People living with dementia described difficulties coping with a loss of independence, as well as a perceived stigma and fear of dementia. Everyone interviewed acknowledged the improvement the available services could make to the management of dementia and consequently their quality of life.

Background and methodology

This HNA aimed to capture the views of PLWD and their carers – past or present – by building on the approach taken in the 2016 report.

The author attended six 90-minute Tibbs Dementia Foundation support groups across Bedford Borough and Central Bedfordshire. These were all aimed at different groups and included a session for people living with LBD, one in which people with MCI were invited and an online group for those who could not attend in person.

An unstructured interview approach was taken, in line with the 2016 report and the same prompts were used:

- Diagnosis
- Knowledge about services
- Access to services

  - Support for the person with dementia
  - Support for the carer
  - Day to day support
  - Community support
  - Residential support
  - Emergency support
- Quality of life both for the person with dementia and for the carer

Conversations were led by the PLWD and/ or their carers, with prompts used to guide the discussion where appropriate. Due to the nature of the sessions, not all prompts were covered in every interview.

Limitations of this approach include that only those currently accessing post-diagnostic support services were interviewed, therefore people living without any support were excluded.

Notes from the meetings were combined and analysed to draw out themes. As people from Bedford Borough and Central Bedfordshire often attended the same sessions, views have not been divided based on geography except when specific points have been made.

Findings

The key themes arising from the interviews are shown in Table 28 and will be discussed in more detail in the text below.

Table 28 Themes emerging from unstructured interviews

Themes emerging from unstructured interviews		
Accessing activities and support	Awareness of support services	Loss of independence
Interactions with healthcare professionals	Making the most of dementia reviews	Appropriate and tailored support for people living with dementia
Carers' needs	Difficulty navigating the dementia pathway	Administrative barriers
Stigma and fear of dementia	Holistic care	Caring for people living with all types of dementia and appreciating differences between them
	Education and awareness	

Accessing activities and support

"I find it difficult to take my father to support groups because I'm still working a full-time job" – Female carer talking about her father who lives with dementia

Both PLWD and their carers commented on how they sometimes found it difficult to access the support that was on offer.

One person living with dementia liked to keep physically active but said she did not feel confident enough to go the exercise classes on the other side of Bedford from her home. There was a gym opposite where she lived but she could no longer afford to go.

Carers discussed seeking a diagnosis and accessing support services. One carer was told they would have to wait 6-12 months for an appointment at the MAS so chose to see a private doctor and received a dementia diagnosis and medication within days. However, this meant they were not plugged into local authority or NHS support services because they received their diagnosis ‘outside the system’. Another carer spoke of the difficulty taking her father to support groups because she is still working full time. Most of the groups are during the day and her father no longer drives therefore they must rely on Good Neighbour Schemes or trust her loved one to get to the group on his own.

Awareness of support services

“I had trouble finding Tibbs when I was first diagnosed with dementia” – Male living with dementia

PLWD and their carers felt awareness of support services available to support people could be improved.

Many of the PLWD felt there had been a delay after diagnosis before they discovered groups which they attended, such as Tibbs, as well as other support. Feelings were expressed that they would like to have been aware of these services earlier on.

The theme of awareness was also echoed by carers. Some commented on a perceived lack of posters or advertisements for dementia support services in areas such as waiting rooms. When carers spoke of discussions with people working in health and social care, it was also clear they felt staff were not aware of all the available services.

Loss of independence

“I would like to have some help so that I can carry on doing the gardening, but my wife finds it easier to do it herself” – Male living with dementia

A person’s loss of independence following the onset of dementia, and how to deal with this, came up frequently in discussions with PLWD and their carers.

Generally, PLWD wanted to carry on with activities they had done all their life, such as driving or gardening, because it helped them to feel more purposeful. However, they said their carers often found it easier to do the tasks themselves rather than support them to try to do it.

Carers, from their perspective, were very concerned about striking the right balance between preserving their loved-one’s independence and keeping them safe.
Driving was a particular concern, especially in rural areas. Carers commented that healthcare professionals were often reluctant to intervene until advanced stages, and that the three yearly self-assessments for those aged 70 years and older relied on insight into dementia that few people living with the condition possessed. Some had good experiences with the in-person Driving Mobility Assessments, which provide an independent and objective assessment of a person's driving. This took responsibility and burden off carers’ shoulders, as well as preventing arguments or tension arising from taking someone’s keys away from them.
Whether driving or walking, carers spoke of how the ability to navigate disappeared in PLWD. This caused great concern, and one carer had set up a GPS tracker after their loved one had got lost when out walking.

Interactions with healthcare professionals

"When I go to the doctor, they often speak to my carer instead of me" – Male living with dementia

Both PLWD and their carers spoke at length about their interactions with healthcare professionals.

Some PLWD recalled receiving their diagnosis. One person said it felt very rushed, and that the doctor lacked compassion, while another spoke of receiving all the information they needed at the time. Several people who took medication for their condition expressed a desire to have more regular contact with healthcare professionals, as they were particularly concerned as to whether they were still on the right drug or at the correct dose. A common theme from many PLWD, regardless of the subject, was that the healthcare professional often defaulted to talking to their carer instead of them, which left them feeling ignored. Groups such as Clear Voices, where PLWD can talk freely without their carers, were greatly appreciated.

Carers also spoke about their experiences during diagnosis. They expressed a desire for compassionate care and sensitivity to the situation, as it is often a hugely stressful and emotional time for them. Carers valued being listened to, and the use of appropriate language that they and the person living with dementia could understand. A more general point was made that carers often found it difficult speaking honestly about someone living with dementia in front of them. This can cause tension if their loved one feels that the carer is being dishonest despite only wanting the best and seeking appropriate help. People expressed a desire to have some time alone with healthcare professionals, so they can speak honestly about the situation, otherwise small declines may be missed if they do not think 'it's worth' the argument with their loved one.

Both PLWD and their carers spoke very highly and appreciatively of healthcare professionals more widely, particularly those who went 'the extra mile' and provided excellent support.

Making the most of dementia reviews

"I didn't realise it was the dementia review until I had put the phone down" – Female carer talking about her dementia review

The subject of the annual dementia review with GPs was brought up consistently by carers at focus groups. Despite happening frequently enough to meet QOF targets, carers felt they could be made more helpful and better address the needs of PLWD. Comments included that the reviews were vague and not tailored to the individual and also that the quality was inconsistent. Some people who had positive experiences described pre-arranged, face-to-face reviews with a HCP which gave them time to prepare and discuss any concerns during the review. Many of those who felt the process could be improved recalled unannounced telephone calls, with the impression that these were opportunistic reviews when HCPs had a few minutes between other commitments. One carer appeared distressed when recalling Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) discussions during the review. While acknowledging it is important to engage in future care planning and discuss topics such as this, the carer wished it had been approached more sensitively.

Appropriate and tailored support for people living with dementia

"I prefer activities which involve moving around but no one else in my care home is able to do them with me" – Female living with dementia

Both PLWD and their carers talked about how sometimes when support was provided specifically to them, it was frustrating because it was not wholly appropriate or tailored to the individual.

One person living with dementia was a visually impaired care home resident, and expressed frustration because they enjoyed being physically active, but activities to support her with this were hard to come by. Many sessions in the care home involved drawing or table-top activities requiring a level of vision which precluded her from participating.

Carers also commented on how services and support could be made more appropriate for individuals living with dementia. Suggestions included minimising the number of different settings appointments took place in, written instructions or explanations to accompany verbal statements and adapting visits or appointments to an individual's needs. This may include care visits at particular times of day to respect someone's routine and ensuring memory screening accounts for factors such as a higher level of education. Several carers expressed a desire for more care at home, both to minimise disruption to someone living with dementia but also to allow those who cannot leave the home for behavioural, physical or other reasons to access the same level of support.

Carers' needs

"I have been a carer for 8 years – it is a 24 hour, 365 days per year job with no let-up" – Male carer for his wife who lives with dementia

The needs of carers themselves were raised on many occasions during the focus groups. PLWD also acknowledged this, for example those attending the Clear Voices group commented that they appreciated the respite carers got during the support group.

Carers discussed ways in which some of their needs were met. This included peer support through groups such as Carers in Bedfordshire and Tibbs, which allowed problem-solving without seeking formal support. Help with household tasks by agencies such as AgeUK was also appreciated. The DISS team were praised for meeting the needs of carers in crisis, and also for helping to arrange ongoing social care support. The carer's allowance was described as allowing dedicated respite time, and opportunities for carers to leave the house alone whether that be to do tasks such as shopping or engage in social activities. The role of paid carers, who can come because of the carer's allowance, was also discussed. Some were praised for simply acting like a friend of a PLWD, playing monopoly or dominoes for example. It makes it much easier for carers when they can say a friend is coming over, as their loved-one may refuse a 'carer', saying they don't want or need it. While these services were appreciated, carers acknowledged that they did not always keep up with demand.

An unmet need which was raised on numerous occasions was the difficulty in carers getting appointments for themselves, who are often also older people with increased risks of many health issues. Accounts were given of exhausting attempts to find people or carers to look after their loved ones while they sought treatment, with particular difficulty if they needed to stay overnight in hospital, for example. Some also described how last-minute cancellations further increased troubles, as not only do they need to make different arrangements for themselves but also the person being cared for.

Difficulty navigating the dementia pathway

"I think a navigator would be useful, to guide me through all the activities and opportunities which are available" – Male living with dementia

The perception of a fragmented dementia pathway was encountered several times in discussions with PLWD and their carers. PLWD discussed finding it hard to take all the information in at the MAS, and how they would value someone who could help them navigate the different support services.

Carers offered more specific experiences and suggestions. Many expressed feeling lost after being discharged from the MAS. They would have valued more time to discuss support, in appointments separate to those when they receive the diagnosis. They appreciated the sizeable information packs provided by the MAS, but sometimes found the content within hard to interpret and did not have full insight as to what was most appropriate to access at any one time.

The concept of having a single point of contact or access was raised several times. People discussed having difficulty understanding and accessing various services and would value having a care co-ordinator or similar. Similarly, many people wished for greater sharing of information between services as they could not always recall what they had said to whom and it was burdensome to repeat the same information multiple times. Finally, where possible, many carers expressed a preference for a proactive, opt-out approach. For example, automatic referral from the MAS to support services following diagnosis and carers being proactively contacted and offered support.

Administrative barriers

"It is almost impossible to fill out all the forms without some help" – Female carer

The difficulty associated with legal and administrative processes, such as arranging lasting power of attorney and applying for attendance allowance, was raised by carers. When someone is diagnosed with dementia, it is often a trigger to arrange many of these, some of which are more specific to dementia than others. These were felt by many to be overly difficult, and several carers turned to the voluntary sector for help completing them. There was a sense that others, who were not aware of how or where to seek help, may miss out on certain benefits.

Stigma and fear of dementia

"I want people to tell me what I can do, not what I can't" – Male living with dementia

Many people, those living with dementia and their carers, discussed issues surrounding stigma and fear. PLWD spoke about a desire for a 'can do' attitude from everyone providing care. Some felt that too much focus on what people could not do may lead to PLWD adopting this attitude, thus lowering their self-esteem. Instead, they wanted to focus on activities they could still do and how this may improve their wellbeing. Carers agreed, raising points that there is too much discourse around stigma and fear, and not enough on the promotion of living well with dementia. They wanted acknowledgement that people could still lead a long and happy life, with a peaceful death.

Holistic care

"I had lots of blood tests, scans and examinations but I wonder if they could have done more to look at me as a person" – Male living with dementia

The topic of holistic care was alluded to or explicitly mentioned by several PLWD and their carers. Some of those living with dementia discussed how they had been subject to numerous medical procedures, but often with a narrow focus and felt sometimes more could have been done to assess them as a human being. Carers agreed that holistic care was very important in relation to dementia, given that its effects are wide-ranging. It was discussed how providing support in a range of settings, such as support groups or dementia cafés, could allow a more open discussion of issues which may not be brought up in a medical consultation, for example.

Caring for people living with all types of dementia and appreciating the differences between them

“When I was first diagnosed with mild cognitive impairment I didn’t want to attend ‘Dementia’ branded services” – Male living with mild cognitive impairment

The focus groups involved conversations with people living with MCI and various subtypes of dementia including AD, Vascular Dementia and LBD as well as their carers. A theme which emerged was a sense that a ‘one-size fits all’ approach was used in some services, and this did not appreciate the nuance of different dementia types.

One person living with MCI described how initially they were reluctant to attend services for PLWD, and that they had not received counselling or advice that this was in fact appropriate. After starting Cognitive Stimulation Therapy, they were however very glad to have joined and found this to be a useful activity. Even amongst those living with a formal diagnosis of dementia, there was a reluctance expressed to attend groups if they perceived that others in the group would be living with more severe forms of the disease. This was particularly true for LBD, given the symptoms associated with Parkinsonism are more visible than other dementia subtypes.

Carers also commented on the importance of appropriate support for people living with all forms of dementia. Particular mention was made of difficulties arising when one feels ‘stuck’ between services, especially in relation to LBD. Carers expressed frustration that they could only be cared for by one of neurology or dementia services at any one time, which made them feel as though not all needs could be met.

Education and awareness

“There needs to be more education and awareness across the board” – Female carer

Whenever comments were made, either by PLWD or their carers, many expressed a desire for more education in relation to dementia and for awareness to be raised around this issue more broadly. Feelings were expressed that the quality of care could be improved greatly with a modest amount of education or training for those delivering care. Several people also thought a greater awareness of dementia and the available support could break down barriers for the public to access services.

Section 7 Dementia care in Bedford Borough with reference to NICE guidance

This section identifies specific areas of dementia management where NICE guidance is being met, and others where adherence may be improved.

NICE aims to produce useful and useable guidance which can be used to help practitioners and commissioners get the best care for patients, while ensuring value for the taxpayer.

As discussed in Section 3, NICE have produced two guidelines on dementia: *NG16: Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset* and *NG97: Dementia: assessment, management and support for people living with dementia and their carers.*

Having considered the epidemiology of dementia and evidence base for prevention, described current services in Bedford Borough and explored the views of those delivering and receiving care this guidance will now be revisited. Areas where it appears to be met, and those where gaps may be present, will be outlined. This will focus on NG97 as NG16, although important, is not specific to dementia care.

Where guidance is being met in Bedford Borough

Recommendation	Detail	Comment
1.1 Involving people living with dementia in decisions about their care	1.1.6 Providing information: At diagnosis, offer the person and their family members or carers (as appropriate) oral and written information that explains how they will be cared for and which services they can access.	PLWD and their carers report receiving large information packs at diagnosis. Opportunities are given to PLWD and their carers to attend *Moving Forwards* sessions and use the *Memory Navigation Service.*
1.4 Interventions to promote cognition, independence and wellbeing	1.4.1 Offer a range of activities to promote wellbeing that are tailored to the person's preferences. 1.4.2 Offer group cognitive stimulation therapy to people living with mild to moderate dementia. 1.4.3 Consider group reminiscence therapy for people living with mild to moderate dementia.	Commissioned post-diagnostic support services offer a wide range of activities for PLWD, including cognitive stimulation therapy. Other services which promote independence and wellbeing but are not specific to dementia include day centres, supported living and community organisations.
1.11 Supporting carers	1.11.1 Offer carers of people living with dementia education, training and advice to help	Many of the providers of dementia care offer education and training sessions to support carers.

	support them and the person living with dementia.	Post-diagnostic support services, such as Tibbs Dementia Foundation and Carers in Bedfordshire, offer spaces where carers can come together in a group environment.
1.13 Staff training and education	1.13.1 Care and support providers should provide all staff with training in person-centred and outcome-focused care for people living with dementia. 1.13.2 Care providers should provide additional face-to-face training and mentoring to staff who deliver care and support to people living with dementia.	In Bedfordshire's hospitals, all staff are given training to improve the quality of care for PLWD. Enhanced training is given to those who treat PLWD regularly.

Where adherence to guidance could be improved in Bedford Borough

Recommendation	Detail	Comment
1.1 Involving people living with dementia in decisions about their care	1.1.1 Involving people in decision-making: Encourage and enable people living with dementia to give their own views and opinions about their care. 1.1.11 Providing information: Tell people living with dementia (at all stages of the condition) about research studies they could participate in.	Several PLWD and their carers felt health and care professionals often spoke to the carer rather than the person living with dementia. Some stakeholders commented that there were fewer opportunities to participate in research studies for people living in Bedford Borough.
1.3 Care coordination	1.3.1 Provide people living with dementia with a single named health or social care professional who is responsible for coordinating their care. 1.3.2 Named professionals should develop a care and support plan in conjunction with the	Many PLWD and their carers commented that they would value someone who could help them through the dementia journey. Despite annual dementia reviews taking place, these were felt to be narrow in scope and not a comprehensive assessment of a person's needs.

	person living with dementia, their family members or carers (as appropriate) and specify when and how often it will be reviewed. 1.3.5 Transferring information between services and care settings: Staff delivering care and support should maximise continuity and consistency of care. Ensure that relevant information is shared and recorded in the person's care and support plan. 1.3.6 Making services accessible: Service providers should design services to be accessible to as many people living with dementia as possible.	People delivering and receiving care expressed frustration at the lack of joined-up care, particularly the sharing of information between services. Many services which are offered take place during the working day. People providing care, particularly post-diagnostic support services, commented that people from ethnic minority communities appeared not to make use of the current offer. Some felt male carers were more reluctant to ask for help.
1.13 Staff training and education	1.13.6 Health and social care professionals advising people living with dementia (including professionals involved in diagnosis) should be trained in starting and holding difficult and emotionally challenging conversations.	While many PLWD and their carers expressed great praise and appreciation for the care they had received, several remembered vividly conversations with healthcare professionals they felt could have been handled more sensitively.

Section 8 Recommendations

Revisiting the recommendations from 2016

The recommendations made in the 2016 report are as follows:

1. *Information, support and training is needed throughout the dementia pathway, providing a single point of contact early in the patient journey would be beneficial.*
2. *Services for people with dementia and their carers should utilise a person-centred care approach to ensure the support provided is tailored to the individual's needs.*
3. *Health and social care providers should look to ensure staff training about dementia is appropriate and helpful to increase the patient and carer experience whether inpatient or outpatient.*
4. *Bedford Borough and BCCG (now BLMK ICS) can be a catalyst for dementia friendly communities. This could include:*
    - a) *Increasing awareness of preventive measures e.g. linking dementia to existing key public health campaigns and services.*
    - b) *Increasing awareness of dementia across public services and with private organisations.*

Recommendations from the current HNA

1. **Ensure PLWD and their carers have access to a single point of contact who can help to coordinate their care**

Rationale: PLWD, and their carers, commented on the difficulties they faced navigating support services. Providers also acknowledged they did not always have the time and requisite knowledge to direct people to the relevant services. Being provided with a single point of contact could enable people to direct their own care, taking advantage of all the support available. This could improve the management of dementia in Bedford Borough, enhancing people's quality of life and preventing complications.

Key sections in HNA and examples:

- Suggestions for improvement, Section 5 (Stakeholder views), Page 52
- Difficulties navigating the dementia pathway, Section 6 (The views of PLWD and their carers), Page 62-63
- Recommendation to provide PLWD with a single named care coordinator, Section 7 (Dementia care in Bedford Borough with reference to NICE guidance), Page 66

2. **Make dementia services accessible for all**

Rationale: Dementia can affect anyone in Bedford Borough, and evidence suggests that already marginalised communities may be most at risk of developing this disease. The importance of caring for hidden populations was discussed by stakeholders, therefore services need to be accessible for all. Processes such as audits, service-user involvement and co-production may help Bedford Borough to work towards this recommendation.

Key sections in HNA and examples:

- Prevalence of dementia in different populations, Section 3 (Descriptive epidemiology), Page 27
- Hidden populations, Section 5 (Stakeholder views), Page 48-50
- Suggestions for improvement, Section 5 (Stakeholder views), Page 53
- Issues facing younger people, people from different ethnic backgrounds and people living with a learning disability, Section 5 (Stakeholder views), Page 53-57
- Accessing activities and support, Section 6 (The views of PLWD and their carers), Page 59-60
- Recommendation on making services accessible to as many PLWD as possible, Section 7 (Dementia care in Bedford Borough with reference to NICE guidance), Page 67

3. Meaningful collaboration between dementia services to improve outcomes and experiences

Rationale: There are many services involved in the care of PLWD, and strong connections facilitate better management of PLWD. However, stakeholders recognised that further joined-up services may enable better care, and expressed frustration where work was done in silos. PLWD and their carers were also disappointed when they felt stuck between services or that people were not talking to each other. This recommendation therefore pertains to meaningful collaboration between partners to work towards shared goals. This could involve sharing of information and data where appropriate, and working in partnership to reduce duplication.

Key sections in HNA and examples:

- Discussed by stakeholders in relation to enablers, barriers and gaps in the treatment system, Section 5 (Stakeholder views), Page 47-48, 50-53
- Difficulties navigating the dementia pathway, Section 6 (The views of PLWD and their carers), Page 62-63
- Recommendation on transferring information between services and care settings, Section 7 (Dementia care in Bedford Borough with reference to NICE guidance), Page 67

4. Engage in primary prevention, reducing risk factors for dementia and other conditions

Rationale: Cases of dementia in Bedford Borough are forecast to increase significantly over the next 20 years. Primary prevention, by targeting smoking, obesity and other health behaviours, offers an opportunity to mitigate the potential strain on health and care services by helping people to reduce their risk of developing dementia. This complements much of the existing work being done by BLMK ICB in relation to prevention.

Key sections in HNA and examples:

- Potential reduction in dementia cases of 45% through primary prevention, Section 2 (Primary, Secondary and Tertiary Prevention of Dementia), Page 10-14
- Prevalence of modifiable risk factors in Bedford Borough, Section 3 (Descriptive epidemiology), Page 30-35
- Guidance on approaches to delay or prevent onset, Section 7 (Dementia care in Bedford Borough with reference to NICE guidance), Page 65

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