

# Worcestershire Health and Well-being Board Dementia Joint Strategic Needs Assessment (JSNA)

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## Summary of Findings and Recommendations

- There are an estimated 8,306 cases of dementia in those aged  $\geq 65$  in Worcestershire
- Only 4,814 cases (55.8%) are currently registered with a diagnosis of dementia
- This may mean people with the condition, and their carers, are not getting access to the right treatment and support they need
- The number of people with dementia is set to increase to **11,257** by 2028, and **14,382** by 2038
- The largest increase will be in those aged 85+, who are more likely to have increased care needs
- Almost a third of dementia cases could be prevented by addressing modifiable risk factors in mid-life
- These include smoking, increased alcohol consumption, obesity, physical inactivity and unhealthy diet. Several services are already in place to address these
- There is variation throughout the county with the frequency and management of these risk factors
- A comprehensive action plan is already in place to tackle this under-diagnosis led by the Worcestershire CCGs.
- Further work is required to ensure care plan reviews are completed in a timely way for everyone with dementia
- There appear to be sufficient numbers of care home placements suitable for people with dementia. However, this will need to increase as need rises.
- There is an expressed lack of respite care available in the county
- There are a variety of services available to support those with dementia and their carers, including advocacy and carer support. However, substantially fewer numbers of people are using the services than would be expected
- Lack of detailed routine collected data throughout the health and social care economy presents challenges for planning, commissioning and monitoring specific services
- Services for people with young onset dementia are substantially under-utilised, and substantial work is required to ensure this particular group are diagnosed and supported appropriately.

- **Aspiration:** People in Worcestershire should have
  - The knowledge, opportunities and skills to reduce their risk of dementia
  - Be diagnosed earlier if they develop dementia
  - Access and knowledge of the correct services to support them and their carers to live well in their communities
  - Be helped to plan for their future, and supported with the correct services for end-of-life care

	<b>Gap/opportunity</b>	<b>Key recommendations</b>	<b>Action lead</b>
<b>PREVENTING WELL</b>	<p><i>Identifying risk factors</i></p> <ul style="list-style-type: none"> <li>NHS Health Check programme now includes a dementia risk reduction component; coverage of the scheme is 45.0% of eligible persons</li> <li>There is variation between GP practices in the regular monitoring and recording of blood pressure in those aged <math>\geq 45</math></li> </ul> <p><i>Management of risk factors</i></p> <ul style="list-style-type: none"> <li>Considerable variation exists between GP practices in the prevalence of modifiable dementia risk factors</li> <li>Considerable variations exists between GP practices in the optimal management of hypertension and diabetes</li> <li>Digital services which complement traditional services are not yet fully comprehensive</li> <li>Support in the workplace to help employees to live healthily is being promoted through Worcestershire Works Well, however this not yet comprehensive for all employees</li> </ul>	<ol style="list-style-type: none"> <li>Increase NHS Health Checks uptake in the county</li> <li>Improve data collection by NHS Health check providers to include dementia risk reduction message delivery</li> <li>Close working across primary care community to discuss the barriers/facilitators to risk factor identification</li> <li>Generate a local campaign across health and social care economy, led by Public Health, to inform the public about dementia risk reduction</li> <li>Close monitoring of core dementia risk factor management (diabetes, blood pressure, obesity and smoking) to continue, and consider facilitating sharing best practice from practices with QOF-based evidence of better risk factor management</li> <li>Continue to integrate dementia risk reduction as digital services for health promotion are developed</li> <li>Continue to promote uptake of Worcestershire Works Well, and consider integration of dementia risk as part of core message, in alignment with NHS Health Checks</li> </ol>	<ol style="list-style-type: none"> <li>Public Health (WCC) commissioners &amp; providers</li> <li>Public Health commissioners &amp; providers</li> <li>CCG &amp; GP clinical leads and/or practice managers</li> <li>Public Health, WCC</li> <li>CCG primary care commissioning</li> <li>All agencies</li> <li>Public Health</li> </ol>

	Gap/opportunity	Key recommendations	Action lead
<b>DIAGNOSING WLL</b>	<p><i>Under-diagnosis</i></p> <ul style="list-style-type: none"> <li>The current level of under-diagnosis of dementia in those aged <math>\geq 65</math> in the county is <b>55.8%</b></li> </ul> <p><i>Diagnostic services</i></p> <ul style="list-style-type: none"> <li>The number of people with dementia is estimated to increase by 35% in the next decade</li> <li>Those aged <math>\geq 85</math> with dementia are not diagnosed in the memory clinic service currently, but instead are probably diagnosed by GPs</li> <li>There has been a recent re-design of the Older Adult Mental Health pathway, including the creation of the Dementia Assessment and Support Team</li> </ul> <p><i>Post-diagnostic services</i></p> <ul style="list-style-type: none"> <li>The majority of referrals historically are from specialist memory services, with very few GP referrals</li> <li>The current case load and annual number of referrals to the Dementia Advisory Service is substantially fewer than the estimated number of incident cases</li> </ul>	<p>8. Dementia Partnership Board to continue implementation of the action plan for under-diagnosis designed by NHS Mental Health Intensive Services team</p> <p>9. Ensure there is sufficient capacity to meet with the expected increase in demand particularly in the OAMH re-design, and that any service developments in the Memory clinics are in line with Memory Services National Accreditation Programme (MSNAP)</p> <p>10. Support primary care in diagnosing dementia in the elderly, and those with moderate to severe stage dementia</p> <p>11. Further training and education to aid broadening referrals to post-diagnostic support services should be explored in partnership with service providers</p>	<p>8. Dementia Partnership Board</p> <p>9. CCG commissioners and WHCT</p> <p>10. CCG and GP leads</p> <p>11. CCG &amp; service providers</p>

	<b>Gap/opportunity</b>	<b>Key recommendations</b>	<b>Action lead</b>
<b>DIAGNOSING WELL</b>	<ul style="list-style-type: none"> <li>• Larger proportion of DAS users reside in Worcester City or Wyre Forest compared to other areas of the county</li> <li>• Need for diagnostic and post-diagnostic services will be driven by increasing numbers with the condition, and efforts to improve the proportion with a diagnosis</li> </ul> <p><i>General diagnostic pathway</i></p> <ul style="list-style-type: none"> <li>• Current pathway is narrow streamed, and may struggle with capacity as need increases</li> </ul> <p><i>Care plan review</i></p> <p>There is substantial variation in the proportion of people with dementia who receive annual care plan reviews (60%-100%)</p>	<p>12. Consider more focussed promotion of post-diagnostic services in areas which are under-represented in current service use (e.g. Malvern, Redditch &amp; Bromsgrove)</p> <p>13. Ensure there is sufficient capacity to meet with the expected increase in demand in post-diagnostic support.</p> <p>14. Consider alternative models of diagnosis pathway (e.g. diagnosis in community; alternative referral sources)</p> <p>15. Develop an action plan highlighting practices with suboptimal levels of dementia care plan reviews, and investigate possible barriers/limitations to care reviews</p>	<p>12. CCG &amp; service providers</p> <p>13. CCG &amp; service providers</p> <p>14. CCG</p> <p>15. CCG in partnership with practice leads</p>



	<b>Gap/opportunity</b>	<b>Key recommendations</b>	<b>Action lead</b>
<b>SUPPORTING WELL</b>	<p><i>Inpatient liaison</i></p> <ul style="list-style-type: none"> <li>• There is no process to ascertain whether those identified as possible dementia through screening are further assessed in primary care</li> </ul> <p><i>Advocacy</i></p> <ul style="list-style-type: none"> <li>• Referrals to the commissioned advocacy service Onside are predominantly from social services</li> </ul> <p><i>Housing</i></p> <ul style="list-style-type: none"> <li>• There are currently care home beds to accommodate 81.5% of the registered number of people with dementia.</li> <li>• Additional funding to facilitate home adaptations, through the Better Care Fund, was conducted through a pilot programme (the Dementia Dwelling Grant)</li> </ul>	<p>16. Consider primary care follow-up audit of individuals identified through inpatient Dementia Assessment and Referral process</p> <p>17. Increase awareness of advocacy services to others, including health professionals, people with dementia and their carers.</p> <p>18. Adult social care commissioners and care home providers should continue to monitor the numbers of beds available for those with dementia, and to prepare for significant increase in capacity requirement across the county</p> <p>19. Commissioners to consider the findings of the Dementia Dwelling Grant evaluation, particularly in the wider economic context of admission avoidance and care costs</p>	<p>16. CCG and WHCT</p> <p>17. Advocacy service providers</p> <p>18. Adult social care commissioners</p> <p>19. CCG commissioner</p>

	<b>Gap/opportunity</b>	<b>Key recommendations</b>	<b>Action lead</b>
<b>SUPPORTING WELL</b>	<p><i>Hospital Care</i></p> <ul style="list-style-type: none"> <li>• Current rate of acute (non-psychiatric) admissions by people with dementia is below the national average. However, this may 'mask' the true picture due to the low numbers with a formal diagnosis, and will also be subject to increasing demands due to more people developing dementia</li> </ul> <p><i>Use of antipsychotics</i></p> <ul style="list-style-type: none"> <li>• Prescription of antipsychotic medication in people with dementia has been consistently higher in Redditch &amp; Bromsgrove CCG in comparison to regional or national levels. NICE guidance recommends limiting prescriptions for antipsychotic medications unless absolutely necessary</li> </ul>	<p>20. Continue to monitor admission rates for people with dementia, and develop contingency plans for probable increases in admissions of people with dementia</p> <p>21. Support initiatives aimed at reducing inappropriate frailty admission as a wider approach to targeting unnecessary admission for people with dementia</p> <p>22. Conduct an audit at practice level of the necessity of anti-psychotic prescriptions, and the timing of prescription of reviews</p>	<p>20. WAHT</p> <p>21. All agencies</p> <p>22. CCG &amp; GP leads</p>

	<b>Gap/opportunity</b>	<b>Key recommendations</b>	<b>Action lead</b>
<b>LIVING WELL</b>	<p><i>Carer Support</i></p> <ul style="list-style-type: none"> <li>• There was expressed need for better provision of respite care for those with dementia. 5 beds (low-level) are available specifically for people with dementia in Worcestershire</li> <li>• Carers Assessment do not record the primary diagnosis of the person being cared for, therefore precluding any analysis of service use and access by carers of people with dementia</li> <li>• It is unclear the amount of psychoeducational therapy which is available and delivered to carers of people with dementia throughout Worcestershire</li> <li>• 2,004 carers registered with the Worcestershire Association of Carers are recorded as caring for someone with dementia; 68% of these are female. Anecdotally, many unpaid carers do not recognise their role as a carer</li> </ul>	<p>23. Assess usage of respite care beds (e.g. days occupied, waiting lists), in addition to comparison to services in other regions</p> <p>24. Explore the expressed need for respite care further with carer groups (see recommendation 28)</p> <p>25. Introduce recording of primary diagnosis on Carer Assessment databases. This should be included within the service specification for current or future providers of Carer Assessments</p> <p>26. Ensure commissioned carer support services are evidence-based, and service monitoring captures the delivered individual activity</p> <p>27. Continue to increase carers' uptake and knowledge of Worcestershire Association of Carers. Explore initiatives to promote uptake of carer support, and make communities (including work environments) more carer-friendly</p> <p>28. Consider a carers needs assessment to inform future commissioning of services</p>	<p>23. Adult Social care commissioners</p> <p>24. Adult Social Care commissioners</p> <p>25. Adult Social Care commissioners</p> <p>26. CCG and adult social care commissioners</p> <p>27. Partnership working between WAC and all agencies</p> <p>28. WCC</p>

	<b>Gap/opportunity</b>	<b>Key recommendations</b>	<b>Action lead</b>
<b>LIVING WELL</b>	<p><i>VCS-led services</i></p> <ul style="list-style-type: none"> <li>• Referrals to Dementia Café predominantly from within Alzheimer's Society, or from diagnostic services</li> <li>• Referrals to Admiral Nursing predominantly from self-referral</li> <li>• All services broadly are not being used by the numbers of people with dementia and/or carers that are present in the county</li> </ul>	<p>29. Consider alternative and innovative approaches, in partnership with commissioners and local interest groups (e.g. Worcestershire Association of Carers), to encourage uptake and referrals to their services from a broader spectrum of the population</p>	<p>29. VCS organisations</p>
	<ul style="list-style-type: none"> <li>• The Dementia Friends initiative has unequal uptake throughout the county. Whilst Dementia Friendly Communities are distributed throughout the county, certain areas of Worcestershire have substantially fewer Dementia Friends</li> </ul>	<p>30. Partners involved in the Dementia Friends initiative should work closely with local partners to improve uptake and engagement of Dementia Friends, to ensure everyone living with dementia in Worcestershire is in a supporting environment. This could involve a focussed roll out to areas with particularly lower numbers</p>	<p>30. All partners</p>
	<ul style="list-style-type: none"> <li>• Areas of the county are not currently incorporated within Dementia Action Alliances (e.g. Tenbury, Pershore).</li> </ul>	<p>31. Dementia Action Alliances or Dementia Friendly Communities should be promoted, particularly in areas currently underserved by these initiatives</p>	<p>31. All partners</p>

	<b>Gap/opportunity</b>	<b>Key recommendations</b>	<b>Action lead</b>
<b>DYING WELL</b>	<p><i>Preferred place of death</i></p> <ul style="list-style-type: none"> <li>There is currently no data available detailing the proportion of people with dementia who die in their preferred place of death, or other end of life care planning discussions (e.g. DNAR decision)</li> </ul>	<p>32. Conduct audit processes to monitor</p> <ul style="list-style-type: none"> <li>a) How many people living with dementia have a preference of place of death recorded</li> <li>b) How many people with dementia die in their preferred place of death</li> <li>c) Whether discussions around end of life have occurred, and the results of these are recorded, enacted and reviewed accordingly</li> </ul> <p>This could benefit from working with the wider Worcestershire palliative care team network</p>	<p>32. Partnership working between Worcestershire palliative care team network, CCG and GP leads</p>



	Gap/opportunity	Key recommendations	Action lead
<b>YOUNG ONSET DEMENTIA</b>	<p><i>ConnectED advocacy</i></p> <ul style="list-style-type: none"> <li>• Connected advocacy services for Young Onset Dementia are used by a limited number of patients, with a disproportionate number in Wyre Forest</li> </ul>	<p>35. Conduct further work to specifically understand the reasons for substantially lower levels of registered people with young onset dementia compared to the estimated. Possible explanations: data error, lack of referral for diagnosis, lack of referral to support services, less public awareness of symptoms causing reduced diagnosis-seeking</p> <p>36. Increase awareness of YOD advocacy services throughout the county to aid uptake of services, in particular outside Wyre Forest, and raise awareness in other professionals and to people with young onset dementia</p>	<p>35. CCG and WHCT</p> <p>36. Advocacy service provider and CCG</p>

# Background

## Dementia

Dementia is emerging as one of the key public health issues of the 21<sup>st</sup> century. A projected 65.7 million people will have the condition worldwide by 2030, and the global incidence is currently equal to a new case diagnosed every four seconds(1). In the U.K, over 1 million adults will have the condition by 2025(2), and dementia recently became the leading cause of death in England and Wales(3). The increasing prevalence of the condition, along with its clinical features and progression, creates an issue for health and social care services of ever increasing significance.

## Clinical Features

Dementia is a neurological syndrome characterised by deteriorating mental function. Impaired function in at least two cognitive domains (e.g. language, visuospatial function, memory) significant enough to effect activities of daily living (ADLs) must be present for diagnosis(4). As well as cognitive function, dementia can affect social behaviours and is therefore associated with complex needs. These can present challenges to carers and social services, and in the later stages of the condition, more difficult issues such as challenging behaviour, wandering, problems with eating and incontinence often manifest(5).

## Causes

Dementia encompasses a variety of different disease processes. The proportion of cases for each subtype of dementia in the UK(6,7) are:

- Alzheimer's disease (~60% of cases)
- Vascular dementia (~15%)
- Mixed dementia (vascular and Alzheimer's concurrently) (~10%)
- Dementia with Lewy bodies (4%)
- Frontotemporal dementia (2%)
- Parkinson's dementia (2%)
- Other e.g. Huntington's disease, prion disease, endocrine disorders (3-5%)

Each subtype has slight differences in clinical features which predominate their presentation, as described in Table 1.



Table 1: Key features of main dementia subtypes (5,7)

Dementia subtype	Key features
Alzheimer's disease	<i>Impairment of episodic memory initially</i>
Vascular dementia	<i>Varied symptoms and signs dependent on location of vascular lesion</i>  <i>Can develop abruptly or gradually</i>  <i>Altered emotions (e.g. mood changes) common</i>  <i>Memory loss less noticeable compared to Alzheimer's disease at onset</i>
Dementia with Lewy Bodies	<i>Complex visual hallucinations and Parkinsonism</i>
Frontotemporal dementia (FTD)	<i>Typically younger onset</i>  <i>Personality and behavioural changes (e.g. social or sexual disinhibition)</i>  <i>Memory usually spared early in disease</i>

An important sub-group of people with dementia are those with young onset dementia (YOD). Defined as those with dementia diagnosed before the age of 65, YOD accounts for approximately 5% of all dementia in the UK(6). YOD has a different spectrum of causes – Alzheimer's disease is still the most common but reduced (~35% vs. 60% of all age dementia); FTD is more common (~10-20%); and rarer causes such as Huntington's disease and Creutzfeldt-Jakob disease combine to account for roughly 10-15% of YOD(1,6).

## Diagnosis

Due to its gradual progression and non-specific symptoms, diagnosing dementia can be challenging. Furthermore, people may be able to compensate for the signs and symptoms of early stage dementia(5), and therefore delay formal diagnosis. Dementia is suspected if a person experiences impaired cognition, difficulties with ADLs, or behavioural and psychological symptoms of dementia (6). These include emotional lability, apathy or motor disturbance.

Initial assessment is undertaken by the General Practitioner (GP). This includes a thorough clinical history and examination, utilising a standardised cognitive assessment tool, and routine blood tests. It is important to exclude any reversible causes of cognitive impairment. If dementia is still suspected, the patient should be referred to a specialist secondary care setting for further assessment and investigation(4).

## Prognosis and Treatment

There is no cure for dementia(6), and mortality in those with a diagnosis of dementia is higher compared to those without, particularly in the first year after diagnosis(7). The number of years of life lost varies depending on the age at diagnosis, but approximately 3-5 years is lost(8).

Progression of disease occurs over several months through stages of severity – mild (some language problems and memory impairment) for year 1-2; moderate (increasing speech difficulty and memory loss, requiring some self-care assistance) from year 2 to 4/5; severe (near complete dependence and inactivity) year 4/5 onwards(1).

Treatment interventions for cognitive symptoms, and non-cognitive symptoms and challenging behaviours, can be either pharmacological or non-pharmacological(4). Table 2 summarises the recommended interventions from relevant National Institute for Health and Care Excellence (NICE) guidance.

**Table 2 Summary of recommended interventions (from NICE guidance 4)**

Intervention	Recommendations
<p><b>For cognitive symptoms and maintaining function</b></p> <p><i>Non-pharmacological</i></p> <p><u>Pharmacological</u></p>	<p><i>Mild/moderate dementia:</i> group cognitive stimulation therapy; group reminiscence therapy; cognitive rehabilitation therapy</p> <p><u>Mild/moderate Alzheimer's disease – acetylcholinesterase inhibitors</u></p> <p><u>Moderate (if intolerant of acetylcholinesterase inhibitors)/severe Alzheimer's disease – memantine</u></p> <p><u>Mild/moderate Lewy body dementia – acetylcholinesterase inhibitors</u></p> <p><u>Other dementias</u> – no routinely recommended treatment</p>
<p><b>For non-cognitive symptoms and challenging behaviour</b></p> <p><i>Non-pharmacological</i></p> <p><u>Pharmacological</u></p>	<p>Psychosocial and environmental interventions to help reduce distress in people living with dementia</p> <p>If severe, or immediate risk of harm: antipsychotics, with close re-assessment and review</p>

## Risk Factors

The development of dementia is associated with both modifiable and non-modifiable risk factors.

Increasing age is the most significant non-modifiable risk factor(9,10). The increasing population of people with dementia is driven by increased life expectancy. Projections of future dementia population are largely determined by the changes in age structure. Other non-modifiable risk factors include learning disabilities, in particular Down's syndrome.

Many of the modifiable risk factors are already attributed to cardiovascular health – hypertension, obesity, smoking, physical inactivity, diabetes(9). Their role as risk factors for dementia are in part due to their vascular effects within the brain, but there are possible non-vascular effects as well, such as neurotoxins from cigarette smoking and impaired clearance of amyloid secondary to diabetes(9). Livingston *et al*(9) undertook a detailed review of possible modifiable risk factors for dementia. The study estimated that 35% of all cases of dementia are attributable to the following risk factors at various stages of life:

- **Early life (<18 years):** less education (primary school education only/none)
- **Midlife (45-65 years):** hypertension; obesity; hearing loss
- **Later life (>65 years):** smoking; depression; physical inactivity; social isolation; diabetes

The management and reduction of dementia risk factors with population-level initiatives, particularly targeted at mid-life age groups, is recommended by NICE clinical guidance(11). This guidance is discussed in further detail in 'Preventing Well' section.

## Impact on Care

Whilst treatment may slow disease progression, people with dementia will inevitably develop more problematic and difficult clinical features. Therefore, the provision of ongoing management is of crucial importance. Care plans, involving the person with dementia alongside their carers, should be used to maintain the person's independence and abilities as much as possible(12,13). Discussions with regards to advance care planning and end of life care preferences are of vital importance.

People with dementia will almost invariably require carers during their disease journey. Professional care services exist and are utilised, but frequently informal carers such as a spouse or adult children, are required to undertake care responsibilities. The 'carer burden' is greater when caring for those with dementia in comparison to caring for someone without (14), largely due to the effects of behavioural and psychological symptoms experienced by the person with dementia(15). Furthermore, many carers are elderly and may require care support themselves. Around 20% of carers are aged 80 or over, and around two thirds of older carers have a health conditions or disability(16). Carer support therefore is a significant consequence of dementia.

The demand on formal care provision due to dementia is immense. Almost 40% of people with dementia live in residential or care home settings(2), and the estimated prevalence of dementia in care homes is 64.6%(10). People with advanced dementia may require more specialist care settings in EMI (elderly mentally infirm) care homes to help manage behavioural symptoms, and over 90% of EMI care home residents have dementia(2). Dementia therefore accounts for a

significant proportion of care home capacity, in particular high dependency settings. This places even greater strain on social care currently and in the future, with current projections for over 70,000 extra care home spaces required by 2025 in the U.K to meet the need of ageing population as a whole(17).

## Advanced Planning

Current clinical guidelines emphasise the importance of adapting to the person with dementia's needs, abilities and symptoms to maintain their independence. This should be planned with involvement of the person with dementia and their carers. Resulting care plans should promote this by considering environmental modification to assist independent functioning, accommodate varying abilities and assess planning for ADLs(4,13). Advance care planning is also of crucial importance, and discussions around advance statements, Lasting Power of Attorney and care preferences should be discussed early on if possible, especially whilst the disease is in its less severe stages(12).

## Dementia and Ethnicity

The prevalence of dementia is greater in people with African-American, black-Caribbean or Hispanic background(18). This could be secondary to the elevated rate of several risk factors for dementia (e.g. hypertension, diabetes, stroke and heart disease) in several black, Asian and minority ethnic groups. Worcestershire has a relatively small black and minority ethnic population in comparison to the West Midlands and England (Table 3).

Table 3 Summary of data from Table KS201EW (Ethnic group) from 2011 Census (19)

	<b>Worcestershire</b> (% total population)	<b>West Midlands</b> (% total population)	<b>England</b> (% total population)
<b>Mixed/multiple ethnic groups</b>	1.2	2.4	2.3
<b>Asian/Asian British</b>	2.4	10.8	7.8
<b>Black/African/Caribbean /Black British</b>	0.4	3.3	3.5
<b>Other ethnic group</b>	0.2	0.9	1.0

## Dementia and Learning Disability

People with Down's syndrome are more likely to develop dementia, with earlier onset of symptoms, compared to the general population: 10-25% of 40-49 year olds with Down's syndrome will have dementia, increasing to 75% of those age 60 years and older(20). Those with learning disabilities excluding Down's syndrome are also at increased risk of dementia, to a lesser extent(6,20). Approximately 1 in 10 people aged 50-65 with learning disabilities other than Down's syndrome have dementia, rising to more than half of those aged 85 or over(21).

# Policy Context

## National Policy

There has been a significant policy drive towards improving dementia care, support and research in the U.K since the launch of the first 'Prime Minister's challenge on dementia' in 2012(22). A subsequent update(23) has focussed on four broad areas for improvement: risk reduction, health and care delivery, awareness of dementia, and research. Table 4 summarises the key priorities within each of these themes.

**Table 4: Summary of key priorities for Prime Minister's Challenge on Dementia 2020 (23)**

Theme	Key priorities
Risk reduction	<ul style="list-style-type: none"> <li>- Increase awareness of reducing the risk</li> <li>- Expand the knowledge base on dementia risk reduction</li> <li>- Promote the dementia component of NHS Health Checks</li> </ul>
Health and care delivery	<ul style="list-style-type: none"> <li>- Improving diagnostic rates and time to diagnosis</li> <li>- Support and care post-diagnosis</li> <li>- Helping people live well in their own homes</li> <li>- End of life care</li> </ul>
Dementia awareness	<ul style="list-style-type: none"> <li>- Increase the number of Dementia Friends to 3 million</li> <li>- Develop communities and businesses to be more Dementia Friendly</li> <li>- National and local government to lead public sector dementia awareness</li> </ul>
Research	<ul style="list-style-type: none"> <li>- Increase research funding and capacity</li> <li>- Faster delivery of better treatments</li> </ul>

The diagnostic rate is a measure of the number of people registered with a dementia diagnosis, compared to the estimated number of people with dementia based on estimated prevalence. The national policy states a target of 66.7%, which has been met at the national level. However, there is still considerable variation at local levels of healthcare. A key policy target is to at least maintain this level of diagnosis, and to ensure it is being met throughout the U.K(23).

A further stated aim of the policy is to increase the number of people receiving a confirmed diagnosis within 6 weeks of referral by their GP.

## Well Pathway for Dementia

A central component of the national dementia strategy is the 'Well Pathway for Dementia'. This framework separates dementia care in to five sections (Figure 1). This approach has been integrated throughout the national approach to dementia, such as data presentation within the online Dementia Profiles provided by the Dementia Intelligence Network for Public Health England(24).






NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA				
<b>PREVENTING WELL</b>  Risk of people developing dementia is minimised "I was given information about reducing my personal risk of getting dementia" <b>STANDARDS:</b> Prevention <sup>(1)</sup> Risk Reduction <sup>(5)</sup> Health Information <sup>(4)</sup> Supporting research <sup>(5)</sup>	<b>DIAGNOSING WELL</b>  Timely accurate diagnosis, care plan, and review within first year "I was diagnosed in a timely way" "I am able to make decisions and know what to do to help myself and who else can help" <b>STANDARDS:</b> Diagnosis <sup>(1)(5)</sup> Memory Assessment <sup>(1)(2)</sup> Concerns Discussed <sup>(3)</sup> Investigation <sup>(4)</sup> Provide Information <sup>(4)</sup> Integrated & Advanced Care Planning <sup>(1)(2)(3)(5)</sup>	<b>SUPPORTING WELL</b>  Access to safe high quality health & social care for people with dementia and carers "I am treated with dignity & respect" "I get treatment and support, which are best for my dementia and my life" <b>STANDARDS:</b> Choice <sup>(2)(3)(4)</sup> , BPSD <sup>(6)(2)</sup> Liaison <sup>(2)</sup> , Advocates <sup>(3)</sup> Housing <sup>(3)</sup> Hospital Treatments <sup>(4)</sup> Technology <sup>(2)</sup> Health & Social Services <sup>(5)</sup> Hard to Reach Groups <sup>(3)(5)</sup>	<b>LIVING WELL</b>  People with dementia can live normally in safe and accepting communities "I know that those around me and looking after me are supported" "I feel included as part of society" <b>STANDARDS:</b> Integrated Services <sup>(1)(2)(5)</sup> Supporting Carers <sup>(2)(4)(5)</sup> Carers Respite <sup>(2)</sup> Co-ordinated Care <sup>(1)(5)</sup> Promote independence <sup>(1)(4)</sup> Relationships <sup>(3)</sup> , Leisure <sup>(3)</sup> Safe Communities <sup>(3)(5)</sup>	<b>DYING WELL</b>  People living with dementia die with dignity in the place of their choosing "I am confident my end of life wishes will be respected" "I can expect a good death" <b>STANDARDS:</b> Palliative care and pain <sup>(1)(2)</sup> End of Life <sup>(4)</sup> Preferred Place of Death <sup>(5)</sup>
References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.				
<b>RESEARCHING WELL</b> <ul style="list-style-type: none"> <li>Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change.</li> <li>Building a co-ordinated research strategy, utilising Academic &amp; Health Science Networks, the research and pharmaceutical industries.</li> </ul>				
<b>INTEGRATING WELL</b> <ul style="list-style-type: none"> <li>Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer’s Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.</li> </ul>				
<b>COMMISSIONING WELL</b> <ul style="list-style-type: none"> <li>Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice.</li> <li>Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources.</li> </ul>				
<b>TRAINING WELL</b> <ul style="list-style-type: none"> <li>Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community.</li> <li>Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes.</li> </ul>				
<b>MONITORING WELL</b> <ul style="list-style-type: none"> <li>Develop metrics to set &amp; achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each.</li> <li>Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation.</li> </ul>				

Figure 1 Well Pathway for Dementia, reproduced from the Challenge on Dementia implementation plan(23)

## Local Policy Context

Much of the local policy context has been determined by the national drivers described above. There is no in-date local policy or strategy specifically for dementia in Worcestershire(25), but this is currently being updated for an STP (Sustainability and Transformation Partnership) footprint for Herefordshire and Worcestershire. The current Joint Health and Well-being strategy(26) uses the dementia diagnosis rate as a key performance indicator.

## Structure of the Dementia Needs Assessment

This document will assess the needs of the current and future Worcestershire population with regards to dementia. This process will be separated into the five following components, to reflect the national policy Well Pathway for Dementia: Prevention, Diagnosis, Living Well, Supporting Well and Dying Well.

# Preventing Well

## Description

NICE guidance provides approaches to delay or prevent onset of dementia(11), focusing on targeting mid-life (defined as adults ages 40-64 years old, or those aged <40 from disadvantaged populations). These are focussed around 2 broad areas – promoting healthy lifestyles, and service organisation and delivery. There are 5 core risk factors which require addressing throughout the guidance:

- Smoking
- Physical inactivity
- Increased alcohol consumption
- Unhealthy diets
- Being overweight

A recent Lancet commission analysed the contribution of different factors to the population burden of dementia(9). This identified several modifiable risk factors which in total account for 35% of dementia in the population. These risk factors were grouped in to different stage of life:

### Early life

- Less education (8%) [defined as no secondary school education]

### Midlife

- Hearing loss (9%)
- Hypertension (2%)
- Obesity (1%)

### Late life

- Smoking (5%)
- Depression (4%)
- Physical inactivity (3%)
- Social isolation (2%)
- Diabetes (1%)

## Needs

### Risk Factors

Table 5 shows that levels of physical activity, alcohol consumption and unhealthy diet in Worcestershire are broadly similar to the national and regional picture (accessed from PHE Fingertips 'Public Health Profiles'). There is less data available to investigate the differences in risk factor prevalence within the county, unlike other risk factors.



**Table 5 Prevalence of risk factors in Worcestershire, in comparison to regional and national picture(27,28)**

	Period	Source	England	West Midlands	Worcestershire
<b>Physical inactivity</b> <i>% of physically inactive adults</i>	2016/17	Public Health England	22.2%	25.0%	21.1%
<b>Alcohol consumption</b> <i>% adults drinking &gt;14 units/week</i>	2011-2014	Health Survey for England	25.7%	25.7%	30.2%
<i>% of dependent drinkers</i>	2014/15	"	1.39%	1.46%	1.17%
<i>% of adult binge drinking on heaviest drinking day</i>	2011-14	"	16.5%	15.8%	13.7%
<b>Unhealthy diet</b> <i>Proportion of the population meeting the recommended '5-a-day' on a 'usual day' (adults)</i>	2016/17	Active Lives, Sport England	57.4%	*54.8%	57.5%

Table 6 shows similarities between the 3 CCGs with regards to risk factor prevalence (key to colour labelling is provided on the subsequent page). This shows that level of hypertension, obesity, depression and diabetes are higher than the national average, whilst smoking levels are lower. The percentage of adults aged 45+ who have a blood pressure measurement is better than England in South Worcestershire and Wyre Forest, but worse in Redditch & Bromsgrove. Within the CCGs, there is substantial variation between GP practices with risk factor prevalence (see tables below).

**Table 6 Risk factor prevalence in Worcestershire CCGs (from Quality and Outcomes Framework (QOF) 29)**

	Hypertension	Recorded BP	Obesity	Smoking	Depression	Diabetes
R&B CCG	15.0%	90.3%	10.4%	17.0%	10.9%	6.9%
SW CCG	15.8%	92.3%	10.3%	16.5%	9.4%	7.0%
WF CCG	16.6%	92.1%	11.0%	16.9%	14.2%	7.4%

Key to risk factor prevalence

<ul style="list-style-type: none"> <li>• Hypertension: QOF prevalence (% all ages)</li> <li>• Recorded BP: Patients aged 45+ who have a record of blood pressure (last 5 years)</li> <li>• Obesity: QOF prevalence (% 18+ years old)</li> </ul>	<ul style="list-style-type: none"> <li>• Smoking: estimated prevalence QOF (% 15+ years old)</li> <li>• Depression: recorded prevalence (% 18+ years old)</li> <li>• Diabetes: QOF prevalence (%17+ years old)</li> <li>• <i>Data source: QOF 2016-17 (29)</i></li> </ul>
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Benchmarking: vs. national level

Lower	Similar	Higher		Better	Similar	Worse
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	Hypertension	Recorded BP	Obesity	Smoking	Depression	Diabetes
<b>NHS Wyre Forest CCG</b>	16.6	92.1	11.0	16.9	14.2	7.4
M81068	17.3	92.5	8.7	16.6	17.0	8.2
M81057	21.4	92.0	11.7	14.0	13.7	8.0
M81090	17.0	90.9	10.0	9.1	6.6	5.4
M81010	17.0	91.8	12.2	24.3	17.8	8.3
M81027	14.5	92.5	6.3	8.2	8.1	5.3
M81005	13.8	92.4	10.7	23.3	16.1	7.1
M81015	17.4	92.2	12.6	15.6	13.8	7.3
M81073	19.4	93.6	16.1	15.9	15.4	8.8
M81056	17.6	91.6	11.4	22.2	20.3	8.2
M81608	18.4	93.3	10.6	13.4	8.8	7.3
M81040	18.8	91.1	15.6	18.7	11.9	8.6

	Hypertension	Recorded BP	Obesity	Smoking	Depression	Diabetes
<b>NHS Redditch And Bromsgrove CCG</b>	15.0	90.3	10.4	17.0	10.9	6.9
M81078	14.5	94.7	8.9	6.5	7.6	4.8
M81084	14.4	90.2	12.6	16.2	10.2	6.3
M81070	14.0	90.4	9.9	16.0	10.8	7.5
M81055	16.8	94.8	11.7	20.4	20.4	6.9
M81617	12.9	93.7	14.0	17.2	13.3	5.4
M81069	17.6	87.8	11.9	15.7	8.6	7.7
M81002	14.1	80.2	8.7	21.1	10.5	6.9
M81616	16.1	94.4	11.7	18.5	8.0	7.9
M81041	16.5	90.8	7.1	16.5	9.3	7.4
M81083	20.0	92.7	10.6	11.8	6.7	8.1
M81064	16.6	93.6	9.7	12.8	9.0	6.4
M81089	13.8	91.6	13.3	23.6	11.9	7.4
M81025	14.5	94.8	7.9	16.0	6.5	5.3
M81021	16.0	89.0	10.2	11.5	11.3	5.5
M81001	16.1	90.9	9.8	19.8	15.0	8.0
M81082	12.3	90.1	10.7	16.1	8.9	7.4
M81092	13.0	90.3	7.5	16.7	7.0	6.1
M81020	13.9	87.7	9.3	21.0	8.9	7.5
M81605	12.5	90.2	9.6	11.2	10.5	4.8
M81077	19.2	91.5	6.6	11.3	8.9	5.9
M81087	11.3	91.0	9.0	28.8	10.4	7.6
M81019	15.3	92.3	15.9	21.6	17.7	7.9

	Hypertension	Recorded BP	Obesity	Smoking	Depression	Diabetes
<b>NHS South Worcestershire CCG</b>	15.8	92.3	10.3	16.5	9.4	7.0
M81094	14.7	95.5	14.7	19.5	5.2	6.8
M81046	18.2	92.1	13.2	13.1	10.2	7.4
M81072	15.4	90.2	6.0	17.9	11.3	6.4
M81049	14.5	92.0	7.6	20.2	10.8	6.6
M81029	20.4	92.1	5.8	11.0	5.9	7.2
M81007	20.4	88.9	9.7	8.9	9.5	5.4
M81091	17.0	92.9	13.3	11.3	5.5	7.2
M81627	11.1	89.3	8.3	22.8	7.8	5.8
M81017	10.8	87.2	7.2	27.6	11.9	6.5
Y04968	4.2	91.5	5.5	28.0	11.3	2.2
M81033	13.8	93.3	10.3	9.8	6.6	5.2
Y03602	15.6	94.8	8.7	9.3	8.3	6.1
M81022	14.8	90.8	9.6	17.5	8.8	7.3
M81045	17.8	90.8	7.5	8.4	6.7	6.4
M81075	16.8	92.9	9.0	17.4	10.0	7.5
M81058	18.7	93.9	15.7	21.0	13.0	8.4
M81629	15.2	92.5	7.2	14.9	8.8	6.5
M81011	21.1	95.4	13.1	12.4	9.2	6.4
M81074	19.2	94.9	8.5	14.1	10.7	7.7
M81004	15.5	91.1	10.3	18.8	6.5	6.5
M81034	18.9	91.3	13.6	18.1	12.3	8.4
M81006	12.6	92.2	10.6	14.6	11.1	6.3
M81047	15.6	93.6	14.6	17.8	10.7	8.5
M81008	14.0	91.0	11.2	21.1	12.7	7.7
M81063	16.6	93.4	15.4	16.0	9.0	6.9
M81035	13.5	92.7	11.7	15.6	11.8	7.0
M81081	19.3	93.9	11.2	17.7	9.3	7.2
M81042	20.0	91.1	11.7	14.5	10.1	6.7
M81037	13.7	91.2	7.9	16.5	4.4	7.7
M81038	21.0	95.2	7.8	12.3	7.9	8.3
M81039	17.1	91.5	5.7	12.9	8.7	6.3

## The key findings:

- Proportions of people with hypertension, diabetes, depression and obesity are in general similar to or higher than the national average. Smoking is predominantly lower levels than the national average.
- Very few GP practices achieve similar or better/lower than the national average across all risk factors
- Some GP practices have several risk factors for dementia which are more common in their registered population than the national average.

There is also significant variation in the clinical management of risk factors (Table 7).

**Table 7 Diabetes and hypertension management at GP practice level (29)**

	Diabetes control* (%)	Hypertension control†(%)
<b>NHS Redditch And Bromsgrove CCG</b>	54.5	82.1
M81078	34.8	84.8
M81084	80.0	85.3
M81070	51.0	83.1
M81055	33.3	81.5
M81616	41.4	81.3
M81617	34.2	82.4
M81069	59.0	82.1
M81002	79.9	74.6
M81041	36.0	81.5
M81083	39.3	83.2
M81064	85.9	85.7
M81089	78.8	84.2
M81025	69.0	83.4
M81021	64.2	82.1
M81001	70.2	80.4
M81082	78.1	88.9
M81092	27.5	80.0
M81020	66.9	78.6
M81605	25.0	86.3
M81077	37.8	77.6
M81087	2.3	79.2
M81019	24.2	84.0
<b>NHS South Worcestershire CCG</b>	61.6	85.1
M81094	83.1	92.7
M81046	69.2	79.8
M81072	56.3	89.2

	Diabetes control* (%)	Hypertension control†(%)
M81049	12.7	86.9
M81029	42.9	90.7
M81007	81.4	86.2
M81091	64.1	86.5
M81627	41.8	87.4
M81017	27.9	81.8
Y04968	31.3	76.6
M81033	56.0	82.8
Y03602	70.7	78.6
M81022	77.0	87.5
M81045	73.2	87.5
M81079	67.2	78.7
M81075	81.1	83.8
M81058	51.8	86.4
M81629	67.8	87.0
M81011	84.1	88.8
M81074	69.4	75.6
M81004	55.8	85.6
M81034	74.8	85.1
M81006	68.8	81.3
M81047	60.0	85.3
M81008	58.8	89.1
M81063	74.8	87.2
M81035	44.3	78.8
M81081	46.0	92.9
M81042	70.4	80.4
M81037	59.5	78.8
M81038	60.6	92.1
M81039	78.8	87.7
<b>NHS Wyre Forest CCG</b>	50.9	82.9
M81068	65.0	84.7
M81057	82.6	81.3
M81090	42.9	81.7
M81010	48.5	78.5
M81027	1.8	79.3
M81065	-	-
M81005	27.9	81.5
M81015	27.1	84.1
M81073	1.7	84.6
M81056	69.4	81.5

	Diabetes control* (%)	Hypertension control†(%)
M81608	63.9	85.5
M81040	66.7	90.3

\*Diabetes control: people with type 2 diabetes who receive all 8 care processes (NICE recommended) †Hypertension control: blood pressure ≤150/90mmHg in people with hypertension

It is also important to consider the potential number of people with undiagnosed risk factors. Recent estimates suggests a significant proportion of people with hypertension are still undiagnosed(30). This means that this risk factor cannot be managed.

- Redditch & Bromsgrove CCG: 17,850 undiagnosed (vs. 26,448 diagnosed)
- South Worcestershire CCG: 33,150 undiagnosed (vs. 48,716 diagnosed)
- Wyre Forest CCG: 12,650 undiagnosed (vs. 20,322 diagnosed)

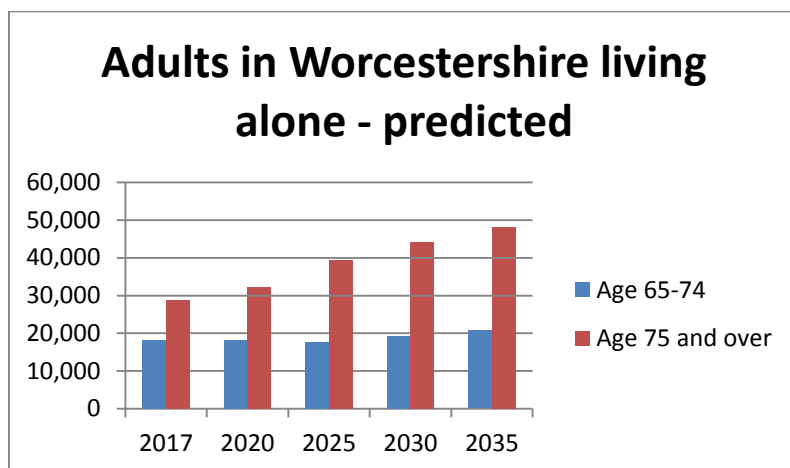
Total diabetes prevalence is thought to be 9.1% in Worcestershire, equalling 43,693 people over the age of 16(31). The actual registered population with diabetes is around 7.0% currently. Therefore, a significant proportion of people with diabetes are currently undiagnosed, again limiting the ability to control this risk factor for dementia. By 2030, 9.9% of people aged 16+ in Worcestershire are estimated to have diabetes, approximately 50,843 people. Therefore, diagnosis of risk factors needs to increase substantially to both meet current need and estimated increased future needs.

### Hearing Loss

The percentage of adults reporting deafness or severe hearing impairment is 3.8% in England. This is statistically comparable within the three 3 CCGs: Redditch & Bromsgrove 4.0%, South Worcestershire 4.3%, Wyre Forest 4.5%. However, within the mid-life aged population, the prevalence may be as high as 32%(9). There is currently lack of evidence to suggest treatment of hearing loss (e.g. hearing aids) alters the risk of dementia in those with hearing loss(32,33).

### Social Isolation

Figure 2 Estimated numbers of adults in Worcestershire living alone



**Source:** Projected Older People Population Information System (POPPI) <http://www.poppi.org.uk/>

There are currently an estimated 46,781 adults over 65 years old living alone in Worcestershire (**Figure 2**). This number is set to increase over the next two decades, with a larger proportion being aged 75 and over.

Work on loneliness in older people was undertaken by the Worcestershire County Council Public Health team in 2016 as part of the JSNA Briefing on Older People(34). This identified the following potential risk factors for loneliness in Worcestershire:

- Geographical isolation
- Long-term illness
- Communal establishment
- Single person households
- Income deprivation
- Unpaid care provision
- Percentage of older people

Based on the distribution of these risk factors, the following areas were identified as high risk for loneliness (Table 8).

**Table 8 Areas in Worcestershire identified as high risk of loneliness (34)**

<b>MSOA name</b>	<b>District</b>
Enfield & Smallwood	Redditch
Droitwich East	Wychavon
Gorse Hill North	Worcester
Bromsgrove East Central (St Johns & Whitford)	Bromsgrove
Batchley	Redditch
Bromsgrove North West (Sidemoor & Norton)	Bromsgrove
Droitwich West	Wychavon
Headless Cross & Oakenshaw	Redditch
Droitwich Central	Wychavon
Moons Moat	Redditch

Age UK have also produced a 'heat map' analysis showing loneliness risk in the over 65 population throughout the Worcestershire districts(35) – see **appendix 1** for detailed maps of all 6 districts. In summary

- All districts have pockets of high risk and low risk
- **Bromsgrove:** not many very high risk areas, but is generally medium risk
- **Redditch:** pockets of high risk, south west of district is lower risk
- **Malvern Hills:** fewer high risk areas compared to others, generally low to medium risk
- **Wychavon:** fewer high risk areas compared to others, generally low to medium risk
- **Wyre Forest:** higher risk in north of district, lower risk east/west
- **Worcester City:** pockets of high risk in the city centre, and generally lower levels around city outskirts.



A loneliness needs assessment is due to be undertaken shortly by the Public Health team.

## Current Services – Commissioned/Non-Commissioned

### NHS Health Checks

Detection of risk factors is being addressed primarily through NHS Health Checks. Recently, dementia risk reduction advice to 40-64 year olds has been added to NHS Health Checks. This intervention is currently advised rather than mandatory. No data is currently collected to identify whether the intervention has been delivered. In Worcestershire between 2014/15 Q1 and 2018/19 Q2, 100% of the eligible population have been offered an NHS health check. The county is performing better than the national average for coverage of this service (45.0% of eligible population vs 38.9%) but there is still clearly room for improvement, and uptake is below the national average (37.5% vs. 48.0%)(36).

### Risk Factor Management

Primary care undertakes the majority of management for risk factors associated with general health. These include hypertension, obesity and diabetes.

Other services also help address these factors and screen for risk factors. Table 9 summarises the recommendations for local authorities and commissioners for risk factor management from NICE guidance(11), and compares these to current services provided in the county.

**Table 9 Summary of recommendations for NICE dementia prevention guidance (11), matched with current service provision**

RECOMMENDATION	FURTHER DETAIL	CURRENT SERVICE
1. Encourage health behaviours	<ul style="list-style-type: none"> <li>Develop and support population-level initiative to reduce risk, making it easier for people to: stop smoking, be more physically active, reduce their alcohol consumption, adopt a healthy diet, achieve and/or maintain a healthy weight.</li> <li>Use local regulatory options and legal powers to encourage increased adoption of health behaviours and risk reduction e.g. Healthy Places</li> <li>Make risk reduction accessible, affordable and acceptable as possible</li> </ul>	<p><i>Public Health</i></p> <ul style="list-style-type: none"> <li>Provision of free to access Health Walks</li> <li>Physical activity and other lifestyle based campaign promotion to the general population nationally (e.g. Stoptober, Change4Life, OneYou)</li> <li>Living Well service</li> </ul> <p><i>NHS</i></p> <ul style="list-style-type: none"> <li>Provision of Smokefree services</li> </ul>

RECOMMENDATION	FURTHER DETAIL	CURRENT SERVICE
<p>2. Integrating dementia risk reduction prevention policies</p>	<ul style="list-style-type: none"> <li>• Include dementia in strategy documents aimed at preventing other non-communicable chronic conditions</li> <li>• Make it clear that some common unhealthy behaviours can increase the risk of dementia</li> <li>• Ensure interventions and programmes to prevent non-communicable chronic conditions state that the risk of dementia can be reduced by encouraging healthy behaviours</li> </ul>	<ul style="list-style-type: none"> <li>• NHS Health Checks</li> <li>• Highlighted in Mental Health and Well-being strategy</li> </ul>
<p>3. <i>[Raising awareness of risk of dementia]</i></p>	<p><i>Not identified within local authority/commissioners remit</i></p>	
<p>4. <i>[Producing information on reducing the risks of dementia]</i></p>	<p><i>Not identified within local authority/commissioners remit</i></p>	
<p>5. Preventing tobacco use</p>	<ul style="list-style-type: none"> <li>• Make smoking tobaccos less accessible, affordable and acceptable</li> <li>• Extend smoke-free policies into a wider range of public places, for example public parks, open-air markets and sports grounds</li> <li>• Promote, and support people to establish and maintain smoke-free homes and cars</li> <li>• Make all health and social services smoke free</li> <li>• Continue to commission smoking</li> </ul>	<ul style="list-style-type: none"> <li>• Legislation on smokefree cars &amp; public spaces</li> <li>• Smokefree parks programme in 2016 covering parks in the County</li> <li>• Smokefree Hospitals in place</li> <li>• Worcestershire Works Well programme supporting businesses to tackle smoking in the workplace and promote smokefree sites</li> <li>• Pregnancy Stop Smoking service</li> <li>• NHS Smokefree</li> </ul>

RECOMMENDATION	FURTHER DETAIL	CURRENT SERVICE
<p>6. Improve the environment to promote physical activity</p>	<p>cessation services</p> <ul style="list-style-type: none"> <li>• Use new and existing traffic management and highway schemes to make walking and cycling safe and attractive options</li> <li>• Improve existing built environment and new developments to promote physical activity</li> </ul>	<ul style="list-style-type: none"> <li>• Health Impact assessment use in local planning applications</li> </ul>
<p>7. Reduce alcohol-related risk</p>	<ul style="list-style-type: none"> <li>• Make alcohol less accessible, affordable and acceptable</li> <li>• Make best use of local information, such as alcohol-related injuries and crime, to develop local alcohol strategy</li> <li>• Ensuring plans include screening and brief interventions for hazardous and harmful drinkers</li> </ul>	<ul style="list-style-type: none"> <li>• Your Life Your Choice</li> <li>• One You</li> <li>• Swanswell Recovery Partnership</li> </ul>
<p>8. Supporting people to eat healthily</p>	<ul style="list-style-type: none"> <li>• Reducing availability and promotion of foods that can contribute to an unhealthy diet e.g. reduce/limit number of food outlets which sell such foods</li> <li>• Helping people to understand what constitutes a healthy diet</li> <li>• Improving access to affordable fruit and vegetables and information on how to prepare them</li> </ul>	<ul style="list-style-type: none"> <li>• Using Health Impact Assessments in local planning applications</li> <li>• Part of national campaigns to promote healthy eating options (e.g. One You)</li> <li>• Regulatory Services have a 'Healthier Choices Food Award' to help businesses promote healthier options to patrons</li> <li>• Living Well service</li> </ul>
<p>9. Delivering services to promote behaviour change</p>	<ul style="list-style-type: none"> <li>• Ensure programmes to prevent non-communicable chronic diseases share resources and</li> </ul>	<ul style="list-style-type: none"> <li>• Living Well service</li> <li>• Healthier You programme (pre-diabetes management)</li> <li>• One You</li> <li>• Your Life Your Choice</li> </ul>

RECOMMENDATION	FURTHER DETAIL	CURRENT SERVICE
	<p>expertise nationally and locally to maximise coverage and impact</p> <ul style="list-style-type: none"> <li>• Work together to deliver services that address the needs of people with multiple risk factors as well as for those with single risk factors</li> <li>• Emphasise the need for, and help people to maintain, healthy behaviours throughout life</li> <li>• Help people identify and address their personal barriers that prevent them from making changes to improve their health</li> <li>• Make information and services available to all (see the Equality Act 2010). Additionally, target these towards those with the greatest need whenever possible</li> <li>• Use audit to help improve the effectiveness of services.</li> </ul>	
<p>10. Provide accessible services</p>	<ul style="list-style-type: none"> <li>• Work with local communities to understand the range of services they need to reduce risk</li> <li>• Provide services at convenient times and easily accessible places</li> <li>• Provide digital services to complement traditional services</li> </ul>	<ul style="list-style-type: none"> <li>• Information and Advisory services provided by WCC</li> <li>• Digital Inclusion</li> </ul>

RECOMMENDATION	FURTHER DETAIL	CURRENT SERVICE
	<ul style="list-style-type: none"> <li>Provide information in range of languages and culturally acceptable styles</li> </ul>	
11. Provide advice on reducing the risks of dementia at every appropriate opportunity	<ul style="list-style-type: none"> <li>Use routine appointments and contacts to identify people at risk</li> <li>Take advance of times in people's lives when substantial change occurs</li> <li>Advise people on how to reduce risk factors whenever the opportunity arises</li> </ul>	<ul style="list-style-type: none"> <li>Making Every Contact Count (MECC) raises awareness of lifestyle risks, behaviour change and public health prevention</li> <li>Dementia Friends programme highlights how to support individuals and spot early signs of Dementia</li> </ul>
12. Providing physical activity opportunities	<ul style="list-style-type: none"> <li>Encourage recreational activities and active travel</li> <li>Provide supervised activities and exercise classes and an infrastructure to support walking and cycling</li> <li>Publicise these opportunities, including where they can be found and who to contact for more information</li> </ul>	<ul style="list-style-type: none"> <li>Provision of information and awareness campaigns on local physical activity opportunities</li> <li>Sports Partnership Herefordshire and Worcestershire have an activity finder to find numerous local activity and exercise opportunities in the County including Park Runs and seated exercise</li> <li>Provision of free to access Health Walks</li> <li>Postural Stability Classes</li> <li>Local district councils with leisure service providers</li> </ul>
13. Provide training	<ul style="list-style-type: none"> <li>Commission and provide training and CPD programmes for local authority staff, all health and social care professionals, relevant third-sector staff and community volunteers to help reduce risk factors.</li> <li>Train participants to provide brief advice</li> </ul>	<ul style="list-style-type: none"> <li>MECC delivered through large organisations through a Train the Trainer programme and e-learning including County Council, Acute Trust, University of Worcester and Health and Care Trust.</li> </ul>
14. Leading by example in the public sector	<ul style="list-style-type: none"> <li>Ensure procurement, commissioning and other policies encourage and</li> </ul>	

RECOMMENDATION	FURTHER DETAIL	CURRENT SERVICE
	support healthy living	
15. Providing support in the workplace	<ul style="list-style-type: none"> <li>Develop policies and provide information and support in the workplace to help employees to live healthily</li> </ul>	<ul style="list-style-type: none"> <li>Worcestershire Works Well</li> </ul>

## Recommendations

1. Increase NHS Health Checks uptake in the county
2. Improve data collection by NHS Health Check providers to include dementia risk reduction message delivery
3. Close working across primary care community to discuss the barriers/facilitators to risk factor identification
4. Generate a local campaign across the health and social care economy, led by Public Health, to inform the public about dementia risk reduction
5. Close monitoring of core dementia risk factors to continue, and consider facilitating sharing best practice from practices with QOF-based evidence of better risk factor management
6. Continue to integrate dementia risk reduction as digital services for health promotion are developed
7. Continue to promote uptake of Worcestershire Works Well, and consider integration of dementia risk as part of core message, in alignment with NHS Health Checks

# Diagnosing Well

## Diagnosis

### Description

Diagnosis of dementia can be clinically challenging, due to its insidious onset, varying symptoms, and the ability of patients to compensate for early symptoms. Diagnosis involves an initial cognitive assessment in those suspected of having dementia, with subsequent further specialist investigations(4).

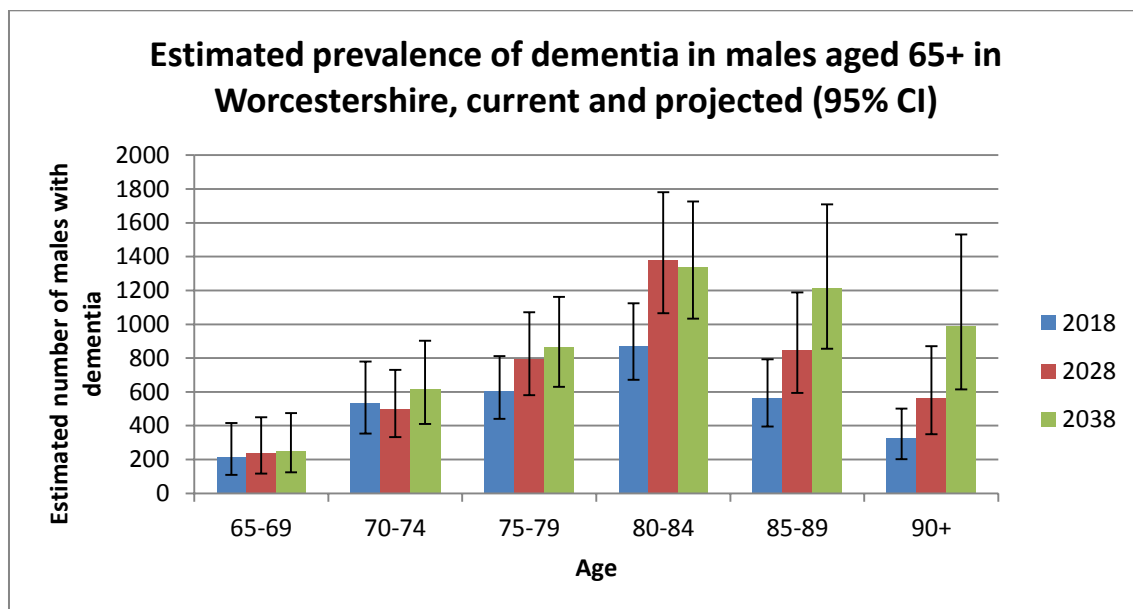
### Needs

There are **4,814 cases of dementia in those aged ≥65 currently registered** on GP databases in Worcestershire. This equates to a point prevalence of **3.63%** (95% CI ±0.10) of the registered Worcestershire adult population aged ≥65. This number has remained fairly static over the last 3 years. However, a significant number of people estimated to have dementia do not have a formal diagnosis. In Worcestershire, there are currently an **estimated 8,306 people aged 65+ who have dementia**, diagnosed or undiagnosed.

### Predicted Numbers of People with Dementia

Figure 3 and Figure 4 show the increase in future estimated numbers with dementia in Worcestershire, if age-related prevalence rates(10) remain stable and are applied to future residential population projections(37).

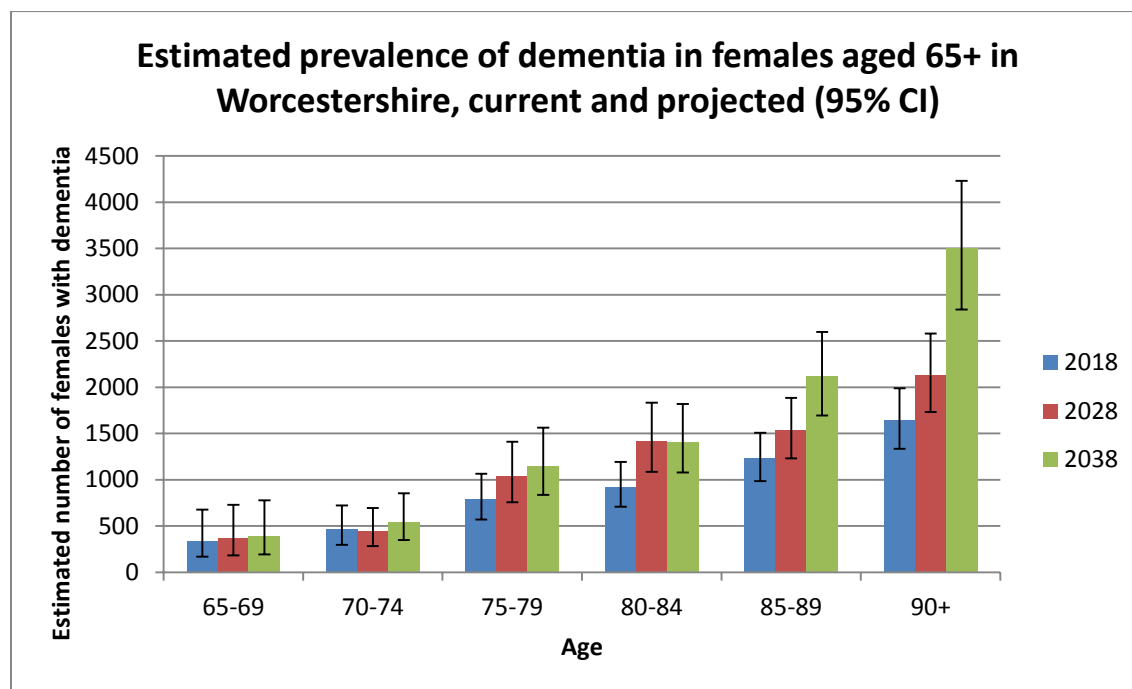
Figure 3 Estimated future prevalence of dementia in males aged 65+ in Worcestershire



Within the 65-84 year old age groups, there is a general increasing trend in the number of dementia cases, however there is no evidence of statistically significant difference. In both male and female subpopulations, there are statistically significant increases in the number of people with dementia in the 85-89 and 90+ categories, between current estimates and 2038.

The number of people with dementia aged 90+ will increase from 329 (95% CI: 201-503) males and 1645 (1335-1988) females to 992 (615-1531) males and 3,500 (2,840-4,230) females by 2038.

Figure 4 Estimated future prevalence of dementia in females aged 65+ in Worcestershire



Overall, these estimates suggest that:

- The number of people with dementia will continue increase substantially
- The biggest proportionate increase will be in those aged 85+

### Under-Diagnosis

The ratio of the number of people who have a diagnosis of dementia compared to the number estimated to have dementia is often referred to as the Estimated Dementia Diagnostic Rate (EDDR). Current national policy states this should be at least 66.7%(23). Based on recent GP dementia registers (July 2018), **the county-level EDDR is 55.8%**.

Estimation of under-diagnosis at GP practice level in Worcestershire shows significant variation in EDDR between practices. Age- and sex-specific prevalence rates (10) were applied to GP registered populations to estimate practice-level prevalence, and compared to recorded dementia diagnosis registers (38) It is important to note however that due to relatively small registered population sizes, these estimates will have wide error margins. Nevertheless, they give an indication of the variation throughout the county.



CCG	Code	EDDR*	CCG	Code	EDDR*
RB CCG	M81078	59%	RB CCG	M81064	44%
RB CCG	M81084	54%	RB CCG	M81089	48%
RB CCG	M81070	47%	RB CCG	M81021	52%
RB CCG	M81055	54%	RB CCG	M81025	48%
RB CCG	M81616	100%	RB CCG	M81077	70%
RB CCG	M81617	53%	RB CCG	M81082	64%
RB CCG	M81069	98%	RB CCG	M81001	36%
RB CCG	M81002	38%	RB CCG	M81092	74%
RB CCG	M81605	85%	RB CCG	M81020	51%
RB CCG	M81041	101%	RB CCG	M81019	49%
RB CCG	M81083	127%	RB CCG	M81087	50%
SW CCG	M81094	64%	SW CCG	M81058	46%
SW CCG	M81046	60%	SW CCG	M81629	61%
SW CCG	M81072	66%	SW CCG	M81011	43%
SW CCG	M81049	52%	SW CCG	M81074	51%
SW CCG	M81029	32%	SW CCG	M81004	47%
SW CCG	M81007	47%	SW CCG	M81034	44%
SW CCG	M81091	68%	SW CCG	M81006	49%
SW CCG	M81627	33%	SW CCG	M81047	48%
SW CCG	M81017	35%	SW CCG	M81008	66%
SW CCG	Y04968	38%	SW CCG	M81063	81%
SW CCG	M81033	32%	SW CCG	M81035	60%
SW CCG	Y03602	34%	SW CCG	M81081	93%
SW CCG	M81022	49%	SW CCG	M81042	69%
SW CCG	M81045	44%	SW CCG	M81037	37%
SW CCG	M81075	61%	SW CCG	M81038	57%
			SW CCG	M81039	83%

CCG	Code	EDDR*	CCG	Code	EDDR*
WF CCG	M81068	46%	WF CCG	M81010	62%
WF CCG	M81057	51%	WF CCG	M81005	53%
WF CCG	M81090	34%	WF CCG	M81015	101%
WF CCG	M81056	66%	WF CCG	M81073	51%
WF CCG	M81027	44%	WF CCG	M81608	55%
			WF CCG	M81040	61%

\*Based on QOF data July 2018 (38) and using age- and sex-specific prevalence rates (10)

Under-diagnosis of dementia in South Worcestershire CCG was analysed by the NHS England Mental Health Intensive Support Team review. The action plan from this review centred around the following themes:

1. Leadership and accountability
2. Commissioning
3. Pathway management
4. Awareness and engagement
5. Monitoring and information
6. Data quality and completeness

The action plan is currently being implemented across all three CCGs through the Dementia Partnership Board.

### Estimated Incidence (New Cases per Year), Current and Future

Early diagnosis is a priority of national dementia policy(23). Therefore, to ensure that diagnostic services are able to review the numbers of new cases expected annually, it is important to examine the number of estimated new cases of dementia per year (incidence). Based on the current estimated resident population of Worcestershire, there are **2,310 new cases of dementia every year** using age- and sex-specific incidence rates(39). By **2028**, this will increase to **3072 new cases per year**, and by **2038** current projected population estimates(37) suggest **3,797 new cases per year**. This substantial increase in new cases, in addition to the already significant numbers of people who are undiagnosed, has significant implications for capacity planning for meeting diagnostic needs.

### Diagnostic Pathway

NICE guidance states the diagnostic process should involve the following steps:

- Initial assessment in a non-specialist (e.g. GP) setting, including using a validated brief structured cognitive instrument
- Onwards referral to a **specialist dementia diagnostic service** (such as a memory clinic or community old age psychiatry service) if reversible causes of cognitive decline/impairments are excluded, and dementia is still suspected
- Within the specialist setting, a dementia subtype should be diagnosed if possible

## Current Services

Service data was reviewed up to April 2018, and therefore the services described were current to this data. Since then, there have been significant changes in dementia diagnostic and support services in Worcestershire as part of the OAMH pathway re-design. Nevertheless, this historical data is useful to demonstrate what needs and demands are likely to be faced by the new service structure.

The pathway for dementia diagnosis was based around GPs referring patients suspected of having dementia to specialist services. Investigation and diagnostic confirmation was conducted by either the Early Intervention Dementia Services (EIDS) or Community Mental Health Teams (CMHT). Those with signs of complexity were referred to CMHT, and those without to EIDS.

Available CMHT data could unfortunately not detail whether the clinical activity was for diagnosis or follow-up. Therefore all CMHT activity data was analysed under 'Supporting Well' section.

### Early Intervention Dementia Service (EIDS)

#### Description

EIDS was facilitated by Worcestershire Health and Care NHS Trust. Before an appointment at EIDS, patients had a pre-assessment meeting at home with a specialist nurse who provided pre-diagnostic counselling. The next two appointments occurred at one of the multiple site clinics run by EIDS throughout the county, and provided an opportunity for further cognitive assessment and diagnostic confirmation. Post-diagnostic support was offered to patients and their families for up to 3 months at the service(40).

EIDS is a current accredited member of the Royal College of Psychiatrists' Memory Service National Accreditation Programme. Review of the accreditation standards(41) showed that adherence to these standards broadly match the NICE recommendations for diagnostic services.

#### Service Use

Patients whose address was registered out of area were removed before analysis. This totalled 47 people for the 2017/18 period, and 36 people for 2016/17. EIDS activity data (Table 10) shows similar numbers of activities and service users over the two year period. The average age of users and the frequency of service use have remained stable, and average time spent in the diagnostic service is 6 to 7 months.

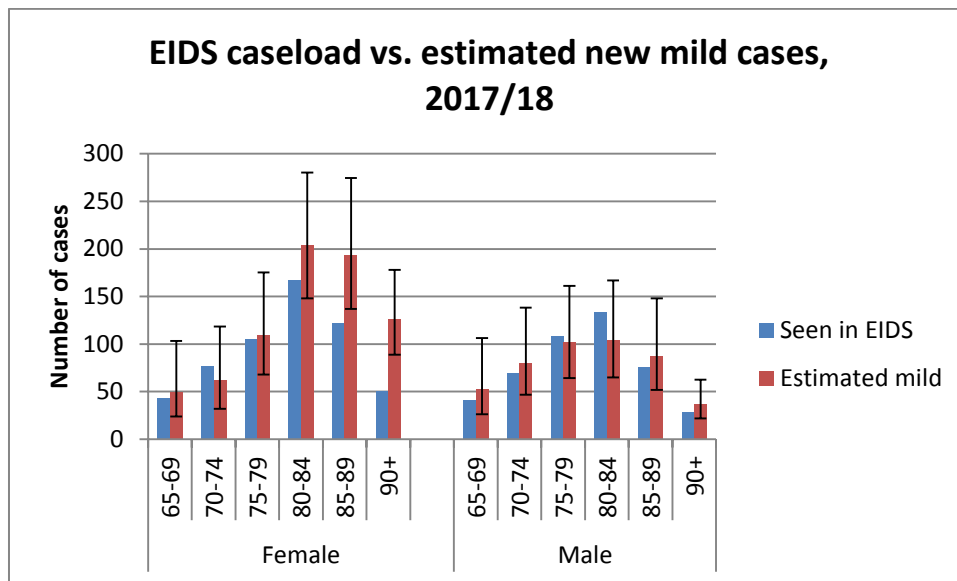
**Table 10 Service data for EIDS, 2016/17 and 2017/18**

	<b>2016/17</b>	<b>2017/18</b>
<b>Number of activities</b>	4754	4,905
<b>Service users (% females)</b>	1,001 (55.3%)	1,020 (55.3%)
<b>Number of visits per user: median (IQR)</b>	3 (4)	3 (4)
<b>Average duration in service (days): median (IQR)</b>	226 (231)	190 (185)

	2016/17	2017/18
<b>Age: mean (SD)</b>	80.1 (6.86)	80.1 (6.83)

Subsequent analysis focussed on data from 2017/18 (Figure 5). The EIDS service was intended for those with non-complex dementia. Therefore, to ascertain whether the service met estimated need, prevalence of mild dementia was calculated, based on differing severity prevalence estimates(2).

Figure 5 Comparison of EIDS service use to estimated incidence of new dementia cases of mild severity



It is not possible to classify those with complex/non-complex dementia without individual clinical details, however as a proxy those with mild dementia are unlikely to have complex dementia.

These comparisons suggest that:

- EIDS service was broadly meeting the need for diagnosis in male patients better than females
- The older age categories (85+) exhibited the greatest difference in estimated cases compared to the number seen.

The difference in those aged 85+ is likely to be met due to GP-led diagnosis. Guidance to GPs from NHS England encourages GP-led diagnosis in those who are unable or unwilling to attend specialist memory clinics who have a clear clinical diagnosis of dementia(42,43). Feedback from local GP and WHCT leads believe that GP-led diagnosis would account for many of those in the oldest age brackets, having their diagnosis in primary care without specialist referral<sup>1</sup>.

<sup>1</sup> Personal discussion at Worcestershire Dementia Partnership Board, October 2018

## Recommendations

8. Dementia Partnership Board to continue implementation of the action plan for under-diagnosis designed by NHS Mental Health Intensive Services team
9. Ensure there is sufficient capacity to meet with the expected increase in demand, particularly in the OAMH re-design, and that any service developments in the Memory clinics are in line with Memory Services National Accreditation Programme.
10. Support primary care in diagnosing dementia in the elderly, and those with moderated to severe stage dementia

## Post-diagnostic Support

### Need

People with dementia and their carers should be offered support in the immediate post-diagnostic period. Current NICE guidelines(4) suggest the following with regards to post-diagnostic support:

- *After a person is diagnosed with dementia, ensure they and their family members or carers (as appropriate) have access to a memory service or equivalent hospital- or primary-care-based multidisciplinary dementia service.*
- *Memory services and equivalent hospital- and primary-care-based multidisciplinary dementia services should offer a choice of flexible access or prescheduled monitoring appointments.*
- *When people living with dementia or their carers have a primary care appointment, assess for any emerging dementia-related needs and ask them if they need any more support*

## Current Services

### Dementia Assessment and Support Team

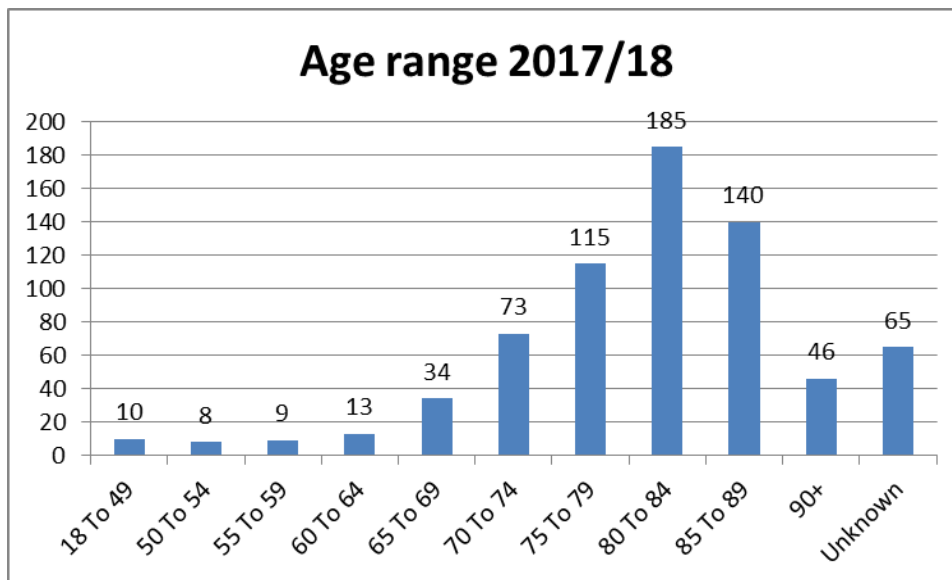
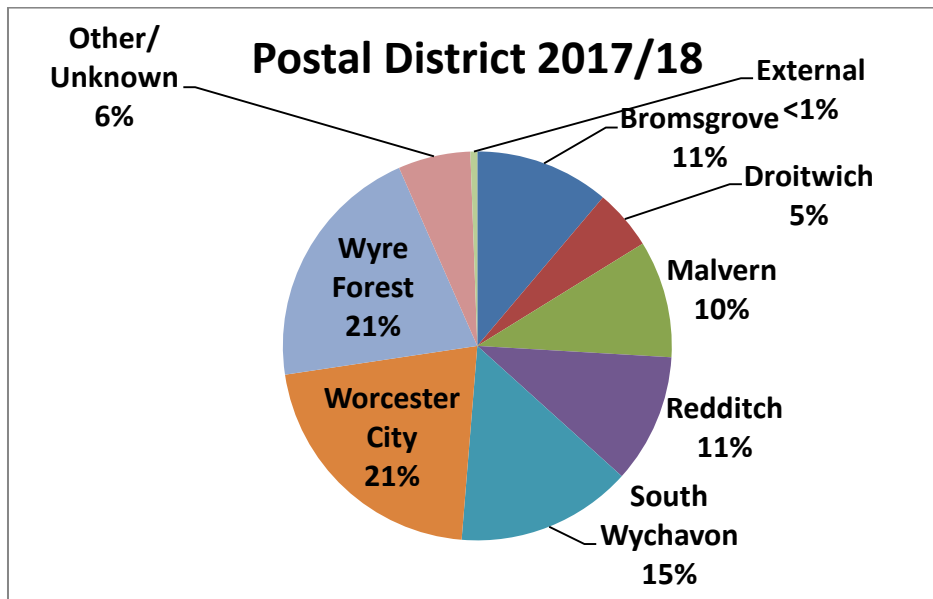
The Dementia Assessment and Support Team (DAST) facilitate the specialist memory clinic service in Worcestershire following the OAMH pathway re-design. In addition to assessment and diagnostic investigation, DAST provides post-diagnostic support to people with dementia and their carers, before care is 'stepped down' back to GPs and the Dementia Advisory Service.

### Dementia Advisory Service (DAS)

Provided by Age UK Herefordshire & Worcestershire.

- There are currently 5 advisors covering Worcestershire, with a case load of approximately 2300 clients in total





The data suggests that:

- The most significant source of referrals has been the specialist memory service
- There is a slight maldistribution of user location, with more service users originating in Worcester City and Wyre Forest.
- The majority of service users are aged 75-89
- The number of referrals (698) is substantially fewer than the estimated incidence of new cases of dementia (~2,300 cases per year).

### Care Plan Review In Primary Care

The review of care plans for people with dementia should be conducted on a regular basis to ensure needs are being met, and to address any emerging issues(4). Annual care plan reviews

of people with dementia is primarily conducted in primary care, and the percentage of people registered with dementia who have an annual review varies significantly by GP practice. Coverage ranges from 60% to 100%, suggesting an unmet need of timely care plan review for those registered with dementia.

<i>GP code</i>	<i>% reviewed</i>	<i>GP code</i>	<i>% reviewed</i>	<i>GP code</i>	<i>% reviewed</i>
<b>M81078</b>	87.5	<b>M81094</b>	73.2	<b>M81006</b>	80.9
<b>M81084</b>	75.9	<b>M81046</b>	75.4	<b>M81047</b>	72.9
<b>M81070</b>	79.2	<b>M81072</b>	84.9	<b>M81008</b>	88.4
<b>M81055</b>	79.4	<b>M81049</b>	71.1	<b>M81063</b>	84.2
<b>M81616</b>	84.4	<b>M81029</b>	82.1	<b>M81035</b>	70.1
<b>M81617</b>	66.7	<b>M81007</b>	76.9	<b>M81081</b>	83.1
<b>M81069</b>	83.4	<b>M81091</b>	89.3	<b>M81042</b>	82.3
<b>M81002</b>	70.2	<b>M81627</b>	77.3	<b>M81037</b>	71.4
<b>M81605</b>	82.8	<b>M81017</b>	78.1	<b>M81038</b>	86.8
<b>M81041</b>	85.9	<b>Y04968</b>	100.0	<b>M81039</b>	84.2
<b>M81083</b>	100.0	<b>M81033</b>	89.7	<b>M81068</b>	92.1
<b>M81064</b>	91.7	<b>Y03602</b>	83.3	<b>M81057</b>	78.4
<b>M81089</b>	78.3	<b>M81022</b>	74.1	<b>M81090</b>	95.0
<b>M81021</b>	72.9	<b>M81045</b>	83.9	<b>M81056</b>	79.7
<b>M81025</b>	77.4	<b>M81075</b>	80.5	<b>M81027</b>	81.7
<b>M81077</b>	75.0	<b>M81058</b>	85.3	<b>M81010</b>	73.4
<b>M81082</b>	75.9	<b>M81629</b>	74.5	<b>M81005</b>	80.8
<b>M81001</b>	85.4	<b>M81011</b>	90.9	<b>M81015</b>	88.4
<b>M81092</b>	87.0	<b>M81074</b>	76.9	<b>M81073</b>	65.5
<b>M81020</b>	75.7	<b>M81004</b>	74.4	<b>M81608</b>	85.7
<b>M81019</b>	85.2	<b>M81034</b>	87.3	<b>M81040</b>	94.9
<b>M81087</b>	60.0				

**Source:** QOF data for 2017/18(44), indicator DEM004

## Recommendations

11. Further training and education to aid broadening referrals to post-diagnostic service should be explored in partnership with service providers
12. Consider more focussed promotion of post-diagnostic services in areas which are under-represented in current service use (e.g. Malvern, Redditch & Bromsgrove)



13. Ensure there is sufficient capacity to meet with the expected increase in demand in post-diagnostic support
14. Consider alternative models of diagnosis pathways (e.g. diagnosis in community; alternative referral sources)
15. Develop an action plan highlighting practice with suboptimal levels of dementia care plan reviews, and investigate possible barriers/limitations to care reviews

## Supporting Well

*'Access to safe high quality health & social care for people with dementia and their carers'*

### Liaison

#### Description

NICE Quality Standard 1 states that:

*People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.*

#### Needs

There were 88,625 admissions in those aged  $\geq 65$  at Worcestershire Acute Hospitals NHS Trust during 2016-17(45). Based on this figure, 5,760 (95% confidence interval: 5229 - 6,204) of these would be estimated to have dementia (diagnosed and undiagnosed).

57,369 admission in those aged 30-64 occurred during the same period. An estimated 134 of these would be estimated to have early-onset dementia.

#### Current Services

##### **Suspected dementia**

A key indicator currently is the Dementia Assessment and Referral data collection(46). This was retired as a CQUIN collection in April 2016, but has been retained in standard contract as a mandatory submission for acute trusts.

Target levels of performance is  $\geq 90\%$  on each of the three indicator components. These are the number and proportion of patients aged 75 and over admitted as an emergency for more than 72 hours:

- i) who have a diagnosis of dementia or delirium or to whom case finding is applied [Find]
- ii) who, if identified as potentially having dementia or delirium, are appropriate [Assess/Investigate]
- iii) where the outcome was positive or inconclusive, are referred on to specialist [Refer]

Worcestershire Acute NHS Trust performs well compared to the national average across all NHS Acute Trusts (Foundation and non-Foundation status) (Table 11) and is above the target 90% level across the three components.

Table 11 Summary of Dementia Assessment and Referral data for 2017-18, NHS England(46)

	<b>% of emergency admissions to whom case finding applied</b>	<b>% with a diagnostic assessment</b>	<b>% of positive/inconclusive diagnostic assessment who are referred</b>
All NHS Acute Trusts	86.32%	93.66%	94.15%
Worcestershire Acute Hospitals NHS Trust	93.89%	92.41%	100%

However, there is no indication of how many individuals who are identified as possible cases are subsequently assessed or referred by their GPs for possible dementia.

### Known Dementia

Approximately 3,000 people with known dementia are admitted to the Worcestershire Royal Hospital annually. Worcestershire Acute Hospitals NHS Trust has a small team of Dementia Clinical Nurse Specialists who lead on the assessments highlighted above, as well as delivering staff training, and providing the following services:

- Advice and support to manage symptoms of dementia
- Psychological support and advice to patients and carers
- Liaison with all members of the MDT involved in the care of the person with dementia, both in the hospital and at home
- Liaison with local dementia care services, such as the Alzheimer's Society and Worcestershire Association of Carers.

The Trust also has access to the Older Adults Mental Health Liaison Team, which provide more broad mental health support for those aged 65 and older.

Personalised care highlighting the specific requirements a person may need due to their dementia is adopted by the trust. 'Forget-me-not' symbols are used to easily identify patients, and 'About Me' booklets are utilised to support the development of individualised care plans.

The Trust also has close links with the Alzheimer's Society, implementing the 'Side by Side' initiative. This project supports people with dementia in hospital by providing volunteers to spend time with them. Once they are discharged, there is a similar project in the community which is available to help reduce social isolation and loneliness.

## Recommendations

16. Consider primary care follow-up audit of individuals identified through inpatient Dementia Assessment and Referral process

## Advocacy

### Description

NICE Quality Standard 30 states:

*People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.*

### Needs

Advocacy ensures that a person's views are represented to ensure their needs are met. Those who provide advocacy should have a good understanding of core issues such as capacity, best interests and advance decisions.

Advocacy is of particular importance for people with dementia due to the cognitive impairment characteristic of the condition. The Mental Capacity Act 2005 established the legal right to advocacy for those who lack mental capacity –this can be provided by Independent Mental Capacity Advocates (IMCAs). Advocacy may be required to assist the person with dementia across a broad range of services - health decisions, financial and legal choices, and end of life/advanced care planning.

Best-practice evidence based NICE guidelines highlight the importance of advocacy services. The availability, rights and access to local advocacy services should be provided through oral and written information to people with dementia and their family members or carers at diagnosis. Named care co-ordinators should also ensure that people with dementia are aware of these rights(47).

Requirements for advocacy services are likely to increase as the number of people with dementia increases. As the number of people with dementia with moderate to severe dementia grows, those who are likely to have capacity issues and therefore require advocacy, is due to increase substantially. Therefore, the proportion of those with dementia requiring advocacy services is likely to increase.

### Current Services

Adult advocacy services are commissioned by Adult Services at Worcestershire County Council, and is currently provided by Onside. This service is not provided exclusively for those with dementia but for all adults in Worcestershire. Four areas of advocacy are provided by Onside:

- Crisis and Issue Advocacy, Care Act and Complaints (NHS & Social Care)
- Independent Mental Health Advocacy
- Independent Mental Capacity Advocacy (IMCA)
- Appropriate Adult service

### Onside activity

In 2017/18, advocacy activity was provided in the following services (Table 12).

**Table 12 Summary of Onside advocacy data 2017-18**

	<b>Number of activities (% total)</b>
Crisis and Issue Advocacy, Care Act and Complaints (NHS & Social Care)	84 (22%)
Independent Mental Health Advocacy	16 (4%)
Independent Mental Capacity Advocacy (IMCA)	273 (71%) of which 248 DoLS-related
Appropriate Adult service	N/A
Blank entry	9 (2%)

The majority of advocacy services for those with cognitive impairments are for capacity advocacy, and the main issue is Deprivation of Liberty Safeguards (DOLS) (Table 13).

**Table 13 Summary of Onside activity details 2015-2018**

	<b>2015 16</b>	<b>2016 17</b>	<b>2017 2018</b>
Referrals	338	307	382
Proportion female	64%	60%	61%
Referral sources (% total)	<b>Social services:</b> 90% <b>Health professional/carer:</b> 7% <b>Other:</b> 3%	<b>Social services</b> 93% <b>Health professional:</b> 3% <b>Family/self:</b> 2% <b>Other:</b> 3%	<b>Social service</b> 91% <b>Psychiatric ward:</b> 5% <b>Health professional/carer:</b> 3%
Geography	Bromsgrove: 12% Malvern Hills: 23% Redditch: 13% Worcester: 19% Wyre Forest: 17% Out of area: 4% Evesham&Persnore: 10%	Bromsgrove: 21% Malvern Hills: 21% Redditch: 9% Worcester: 16% Wyre Forest: 17% Out of area: 3% Evesham&Persnore: 11%	Bromsgrove: 17% Malvern Hills: 17% Redditch: 13% Worcester: 21% Wyre Forest: 13% Out of area: 4% Evesham&Persnore: 11%

## Recommendations

17. Increase awareness of advocacy services to others, including health professionals, people with dementia and their carers

## Housing

### Description

NICE Quality Standards 30 suggests:

*'People with dementia live in housing that meets their specific needs'*

This states that housing should be designed, or adapted, such that people with dementia can manage their surroundings, retain independence and reduce levels of confusion or anxiety.

### Needs

The progressive nature of dementia is such that many people with the condition will develop increasingly complex needs with regards to housing. Difficulties with activities of daily living (ADLs) can develop from neglecting household tasks in early dementia, to difficulties with dressing, eating and walking in later stages(6).

A large array of adaptations in the home are recommended for people with dementia(13,48). These can be broadly categorised into those secondary to reduced mobility and general changes of old age, and those specific to the dementia disease process. For example, improving lighting in the house, easy-to-use bathroom appliances and grab rails aid general mobility. Contrast in floor colouring and removal of patterns, use of bright and contrasting colours for furniture and furnishings but removing stripes and patterns, and visual cues to remember location of items assist with the altered colour perception and memory loss associated with dementia.

The requirement for housing adaption may apply for anyone with dementia, and therefore the need for housing adaption is likely to increase in line with the overall increase in the number of people with dementia.

### Current Services

#### Extra Care housing

Dorothy Terry House, located in Redditch, provides dementia-specific extra care. 42 apartments are available for those living with dementia, as well as couples where one or both have dementia. Adult Social Care at Worcestershire County Council has nomination rights for all of these apartments when vacancies arise.

#### Residential and Nursing home provision

There are currently 100 care homes (nursing and resident) in Worcestershire which have been rated by the Care Quality Commission (CQC) which can provide care for people with dementia. In total, they can provide 3,886 beds(49), therefore 87% of care home beds suitable for people with dementia have been rated by the CQC. The most recent registered numbers (August 2018) of people with dementia is 4768. Therefore there is currently 81.5% coverage of registered dementia population for care home capacity.

In 2017, 94.7% of care home beds suitable for dementia were rated by the CQC in Worcestershire. This was better than the national and regional picture. The number of registered care home and nursing home beds in the county per 100 people registered with dementia was 83.2 per 100 people. This is significantly better than the national and regional levels. A summary is provided in Table 14 below.

**Table 14 Number and quality of care home beds available for those with dementia**

	<b>England</b>	<b>West Midlands</b>	<b>Worcestershire</b>
<b>The number of residential care and nursing home beds per 100 people registered with dementia (aged 65+)</b>	69.2 (95% CI 69.0-69.4)	72.8 (95% CI 72.1-73.5)	*83.2 (95% CI 80.9-85.6)
<b>% of residential care and nursing home beds (suitable for people with dementia) which have been rated by CQC (aged 65+)</b>	88.2% (95% CI 88.1-88.3%)	87.9% (95% CI 87.5-88.2%)	*94.7% (95% CI 93.9-95.3%)

**Source:** <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia>

#### Dementia Dwelling Grant (pilot programme)

The Dementia Dwelling Grant (DDG) was a pilot programme funded from The Better Care Fund by all six participating Worcestershire district councils. It provided small-scale aids and home adaptations which were not available through other programmes. Items included key locators, clocks, touch bedside lights and bath mats. Aids and adaptations did not exceed £750, though provision was made for one-off higher value items if required. Evaluation of the programme is currently being undertaken by the Association for Dementia Studies at University of Worcester, with a final report scheduled towards the end of 2018. Interim findings suggest that small scale aids such as touch lamps and whiteboards can have a positive impact on the wellbeing of people living at home with dementia and their family carers (personal communication, November 2018).

#### Recommendations

18. Adult social care commissioners and care home providers should continue to monitor the numbers of beds available for those with dementia, and to prepare for significant increase in capacity requirement across the county
19. Commissioners to consider the findings of the Dementia Dwelling Grant evaluation, particularly in the wider economic context of admission avoidance and care costs

## Health & Social Services

### Current Services

#### Inpatient (non-psychiatric) admissions

	England	West Midlands	Worcestershire
<b>Ratio of inpatient service use to recorded diagnosis (per 100 registered)</b>	55.1% (95% CI 54.9-55.3%)	61.5% (95% CI 60.8-62.2%)	50.1% (95% CI 48.1-52.1%)
<b>Age-standardised rate of emergency admissions (aged 65+ registered with dementia) (per 100,000 population)</b>	3,482 (95% CI 3,471-3,494)	3,645 (95% CI 3,609-3,682)	2,527 (95% CI 2,441-2,616)
<b>% emergency inpatient admissions for people (aged 65+) with dementia that are short stays (1 night or less)</b>	28.2% (95% CI 28.0-28.3%)	28.0% (95% CI 27.6-28.5%)	27.7% (95% CI 26.2-29.2%)

**Source:** <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia>

Worcestershire has comparably fewer uses of inpatient services by those with a diagnosis of dementia compared to the number of people registered with dementia in the general population. However, this may be artefactual secondary to the low number of people diagnosed with dementia compared to the estimated true number with dementia. The number of emergency admissions of people aged 65+ with dementia is fewer than the national or regional average. The number of short stay emergency admissions (1 night or less) is similar to the national average.

#### Inpatient (psychiatric) admissions

There are three older adult mental health inpatient wards in Worcestershire(50):

- Athelon ward (Worcester)
- Woodland ward (New Haven, Bromsgrove)
- Meadow ward (New Haven, Bromsgrove)

Inpatient care for people with dementia is predominantly provided in Meadow and Athelon wards. Service use in 2017/18 for those admitted to Meadow ward, or Athelon ward with a coding of cognitive impairment, is summarised in Table 15.



Table 15 Summary of psychiatric inpatient activity for people with dementia in Worcestershire

	2017/18
<b>Patients</b>	46
<b>Out of area patients (not included)</b>	<5
<b>Age – average (range)</b>	78.6 (60-94)
<b>Gender (M/F)</b>	31/15
<b>Duration (days) - average</b>	82
<b>Referral source for admission (%)</b>	
<i>GP/transfer from other hospital</i>	21.2%
<i>Mental Health Gatekept*</i>	51%
<i>Mental Health not Gatekept</i>	27.7%
<b>Discharge destination</b>	
<i>Local Authority residential accommodation</i>	5
<i>Care Home</i>	20
<i>NHS (other Hospital)</i>	<5
<i>Patient died</i>	<5
<i>Nil entry</i>	<5
<i>Usual place of residence</i>	11

\*Gatekept = reviewed by Crisis Resolution and Home Treatment team

Worcestershire Health and Care NHS Trust have also adopted the principles of Johns Campaign(51), which gives carers the option to stay with the person with dementia in hospital overnight.

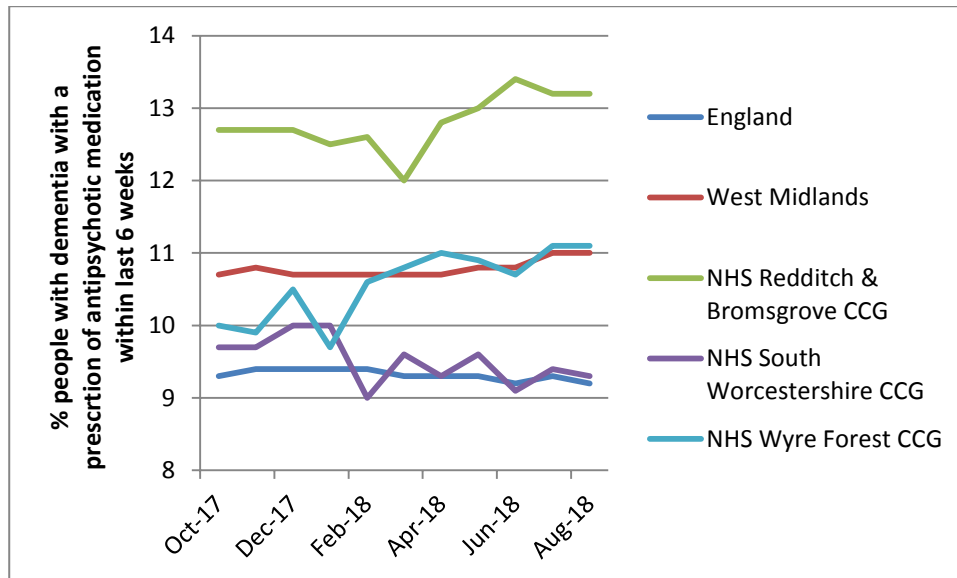
#### Prescription of anti-psychotic medication for people with dementia

NICE guidance recommends against the use of any antipsychotic medications for non-cognitive symptoms or challenging behaviour, unless the person with dementia is either:

- At risk of harming themselves or others **or**
- Experiencing agitation, hallucinations or delusions that are causing them severe distress

The percentage of people with dementia who have been prescribed antipsychotic medications (Figure 6) remains fairly static nationally around 9.3%, and the West Midlands level around 10.7%. Levels in Wyre Forest CCG have started to increase, and Redditch & Bromsgrove CCG have remained consistently higher than the national or regional average. It is not possible to assess whether these levels are due to appropriate use. However, the substantial difference between Redditch & Bromsgrove CCG levels and the rest of the county and country is noteworthy.

Figure 6: Percentage of people with a diagnosis of dementia prescribed antipsychotic medications within last 6 weeks (QOF data (52) )



NICE guidance recommends:

- when antipsychotics are being used the person with dementia is reviewed at least every 6 weeks to ensure the medication is still required.
- to stop treatment if no ongoing benefit is evident
- people living with dementia who experience agitation or aggression should be offered personalised activities to promote engagement or interest

Several possible interventions have been suggested to reduce the inappropriate use of antipsychotic medication(53):

- Policy and regulatory approaches
- Public reporting: NHS digital publish monthly data reports on the percentage of people registered with dementia who have been prescribed antipsychotic medication
- Educational approaches to reducing antipsychotic use e.g educational strategies targeting care home staff and general practitioners, prescribing audit and feedback and medication review

A recent randomised control trial in a U.K setting(54) showed that whilst antipsychotic reviews reduced the use of antipsychotic medications, there was a detrimental effect on the levels of neuropsychiatric symptoms. However, this effect was mitigated by delivering a social interaction intervention concurrently, based on evidence-based approaches to promote social interaction and specific communication skills training to enhance staff-resident interactions.

Examples of interventions to reduce antipsychotic prescription include a GP resource pack, produced by Sussex Partnership NHS Foundation Trust(55). This document provides guidance to GPs on reviewing and stopping antipsychotics, approaches to minimise behavioural problems of dementia, and audit and assessment tools.

## Recommendations

20. Continue to monitor admission rates for people with dementia, and develop contingency plans for probable increases in admissions of people with dementia
21. Support initiatives aimed at reducing inappropriate frailty admission as a wider approach to targeting unnecessary admission for people with dementia
22. Conduct an audit at practice level of the necessity of anti-psychotic prescriptions, and the timing of prescription of reviews

## Living Well

*'People with dementia can live normally in safe and accepting communities'*

### Supporting Carers

#### Description

Quality Standard 1 for dementia support in health and social care from NICE states(12):

*'Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.'*

#### Needs

Nationally, there were an estimated 700,000 carers of people living with dementia in 2014(56). The ratio of informal carers to people with dementia is estimated at around 0.85(56). If this is applied to the current estimated Worcestershire population, there are **an estimated 7,329 carers of people with dementia** in the county. If current prevalence estimates remain the same, **there will be 9,568 carers by 2028** for the estimated 11,357 people with dementia in Worcestershire. Furthermore, this estimate may be an underestimate. The proportion of people with dementia who are aged 85+ will continue to increase significantly, and therefore the proportion of people with moderate to severe dementia will also increase. These groups often have greater care requirements, and therefore the changing composition of dementia severity, in addition to total increasing numbers, will likely increase the number of informal carers in Worcestershire.

Under the Care Act 2014, carers are entitled to an assessment of their own needs and to have these addressed appropriately. Assessments are the responsibility of local authorities, and determining eligibility for support is based around three conditions(57): the need for support has arisen due to the provision of care to an adult; these caring responsibilities are such that the carer's physical or mental health is deteriorating or at risk of deterioration; and this deterioration has a significant impact on the carer's wellbeing. Care plans should be created to ensure the individual's needs are addressed. Interventions can include psychological therapies, psychoeducation interventions and peer-support groups with other carers.

Recent NICE guidance states more broadly the support that should be made available for informal carers of those with dementia(4). Five core recommendations have been identified based on evidence:

1. Offer carers of people living with dementia a psychoeducation and skills training intervention that includes:
  - *education about dementia, its symptoms and the changes to expect as the condition progresses*
  - *developing personalised strategies and building carer skills*
  - *training to help them provide care, including how to understand and respond to changes in behaviour*
  - *training to help them adapt their communication styles to improve interactions with the person living with dementia*

- *advice on how to look after their own physical and mental health, and their emotional and spiritual wellbeing*
  - *advice on planning enjoyable and meaningful activities to do with the person they care for*
  - *information about relevant services (including support services and psychological therapies for carers) and how to access them*
  - *advice on planning for the future*
2. Ensure that the support offered to carers is:
- *tailored to their needs and preferences and to what they want it to achieve (for example, providing information on carer's employment rights for carers who work or want to work)*
  - *designed to help them support people living with dementia available at a location they can get to easily*
  - *provided in a format suitable for them (for example individual or group sessions, or online training and support)*
  - *available from diagnosis and as needed after this*
3. Be aware that carer interventions are likely to be most effective when provided as group sessions.
4. Advise carers about their right to the following and how to get them:
- *a formal assessment of their own needs (known as a 'Carer's Assessment'), including their physical and mental health*
  - *an assessment of their need for short breaks and other respite care .*
5. Be aware that carers of people living with dementia are at an increased risk of depression.

### Expressed needs

Discussions with key stakeholders through the Dementia Care Planning group elicited carer respite and support as key areas of unmet need. In particular, carer respite for those caring for people with early onset dementia was highlighted as an area of concern.

Data from Adult Social Care Outcomes Framework has measured the self-reported quality of life scores for carers of people with dementia. Higher scores suggest fewer unmet needs, with a maximum score of 12.

Compared with benchmark ■ Lower ■ Similar ■ Higher ■ Not compared

**Carer-reported quality of life score for people caring for someone with dementia** 2016/17

Score

Area	Count	Value	95% Lower CI	95% Upper CI
England	17,660	7.5*	7.5	7.5
West Midlands region	1,520	7.5*	7.3	7.7
Birmingham	100	7.1*	6.6	7.6
Coventry	105	6.7*	6.2	7.2
Dudley	90	7.2*	6.6	7.8
Herefordshire	125	7.6*	7.2	8.0
Sandwell	80	6.0*	5.4	6.6
Shropshire	55	7.8*	7.1	8.5
Solihull	105	6.9*	6.4	7.4
Staffordshire	165	8.0*	7.6	8.4
Stoke-on-Trent	95	7.6*	7.1	8.1
Telford and Wrekin	120	7.6*	7.1	8.1
Walsall	100	7.0*	6.5	7.5
Warwickshire	100	7.8*	7.2	8.4
Wolverhampton	135	6.6*	6.2	7.0
Worcestershire	135	7.8*	7.4	8.2

Source: NHS Digital, ASCOF

**Source:** <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia>

This data is highly limited due to a small sample size. Whilst it suggests that quality of life for carers of people with dementia in Worcestershire is similar to the national and regional picture, there is room for improvement in reducing unmet needs.

### Current Services

#### Carer assessments

Carers' assessments are the responsibility of local authorities. Current data does not collect the condition or diagnosis of the person being cared for. Therefore it is not possible to detail how many carer assessments have been completed for carers of people with dementia.

Outcomes from a Carer Assessment to meet unmet eligible needs include:

- Carer Personal Budget
- Identifying need for replacement carer to allow carer respite (this is assessed and purchased through the cared for person's assessment process)

#### Respite

Residential block beds are available for respite in five care homes across the county. Each has 1 dementia block bed, but this is for very low level dementia and they are not in lock door units. For regular respite within the home, replacement care hours can be factored into the care for person's support plan as weekly domiciliary care hours. All forms of replacement care, in order to provide respite for a carer, should be proportionate to the significant impact demonstrated for the carer in line with the Care Act eligibility criteria.

#### Worcestershire Association of Carers (WAC)

WAC is a charitable organisation whose role is to develop and provide quality support and services in response to carer needs throughout the county. The Worcestershire Integrated

Carers Hub, supported by Worcestershire County Council and the three local CCGs, provides a one stop shop for carers.

Services which are provided include:

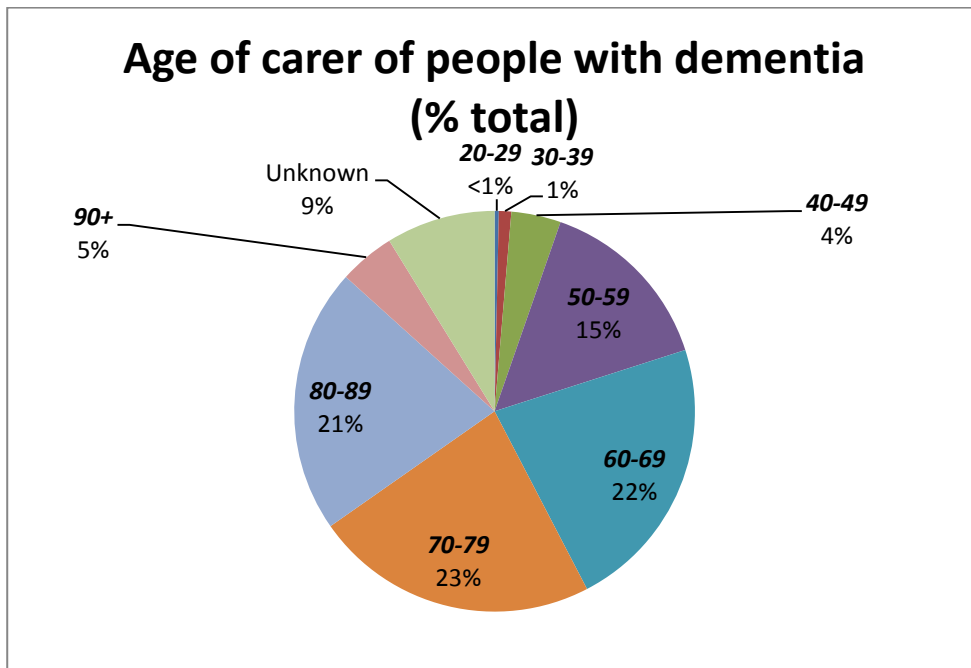
- Carer Pathway Advisors – provide information, advice and support by telephone and drop in information points across the county
- Carer Training – adult carers can access information, advice, support and training tailored to their individual needs (e.g. Caring with Confidence; MoodMaster; Legal and Financial Workshops; Mental Health First Aid; Falls, Fracture and Frailty Workshops)
- Listening Ear – a telephone befriending service which supports those who are caring for someone close to the end of their life
- Carer Talktime – regular telephone contact with a trained volunteer to reduce the isolation that carers can experience
- Carer Groups – support groups help once a month throughout the county.
  - Current locations are: Bromsgrove; Droitwich; Kidderminster; Malvern; Pershore; Stourport; Tenbury; Wythall; Worcester
  - There is also a group specifically for carers of people living with dementia who are in hospital or a care home

WAC currently have **2,004 carers who are recorded as caring for someone with a dementia related illness**. Other carers of people with dementia may not be accounted within this list if dementia is one of a number of conditions and not recorded as the main condition.

The current service users data is summarised in the following tables and figures:

Gender	Number	% total
Female	1365	68
Male	633	31
Unknown	6	1

District	Number	% total
Bromsgrove	306	15
Malvern Hills	300	14
Redditch	265	14
Worcester	315	15
Wychavon	407	20
Wyre Forest	342	17
Out of Area/No post code	69	5



Ethnic group	Number	% total
Asian mixed	15	0.75
White British	1618	80
White Other	24	1.2
Other Ethnic group	36	1.8
Unknown	305	15.2
Do not wish to disclose	6	0.3

\*Several ethnicities had <5 individuals, therefore to preserve anonymity and reduce risk of identification, these were grouped together as 'Other Ethnic group'.

It is noticeable that:

- The majority of carers are female
- Nearly half (49%) of carers of people with dementia are aged 70+, with over a quarter (26%) aged 80+.

#### Admiral Nursing Service

Admiral Nurses provide specialist dementia support, working with people with dementia and their families. The services provided include:

- Targeted intervention – focus on specific interventions, with an emphasis on timely discharge with an open re-referral system.
- Interventions include support and information via contact (telephone triage, clinic, home visit)



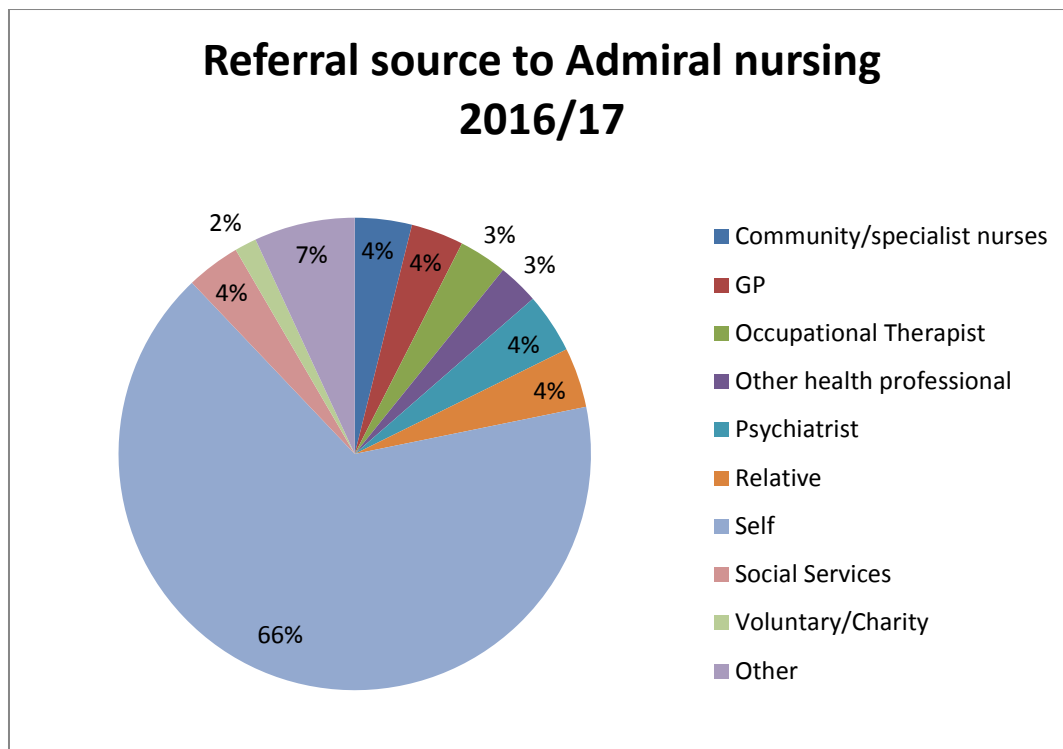
- Joe's Club (Redditch) – run by 2 Admiral nurses, group intervention work, maximum 8 people per session, 2 hours per month

In Worcestershire, there are 5 Admiral nurses (4.6 WTE) based across the county. There is an open referral system, for people with probable or confirmed diagnosis of dementia. The number of referrals has increased in the last two years, however the open caseload has remained relatively stable. For 2016-17 period, the vast majority of referrals come from self-referrals (Table 16 & Figure 7).

Table 16: Summary of Admiral nursing case load, 2014-17

	Oct 2014 – Sept 2015	Oct 2015- Sept 2016	Oct 2016- Sept 2017
<b>Referrals (including re-referrals)</b>	325 (157)	637 (210)	635 (247)
<b>Discharged from service</b>	421	511	547
<b>Open caseload at end of year</b>	205	222	221

Figure 7 Sources of referrals to Admiral nursing, 2016/17



**Dementia Cafes – Alzheimer's Society**

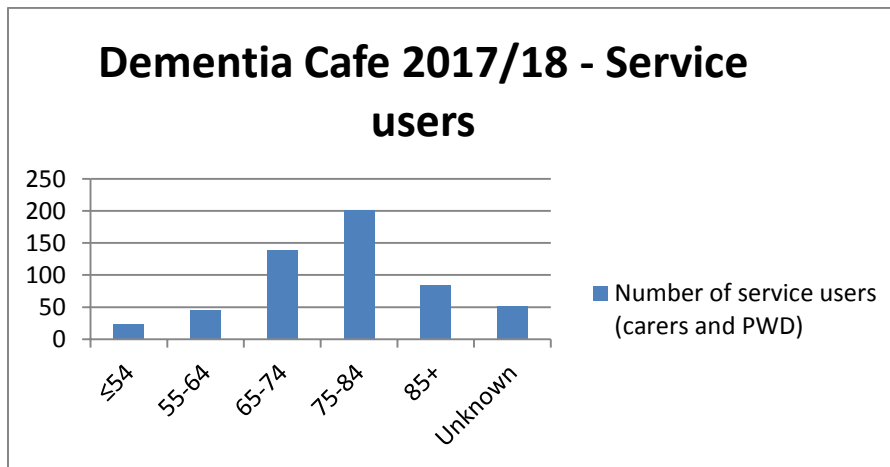
Dementia cafés provide useful information in a structured and informal setting that gives the opportunity for people with dementia, families and carers to ask questions to the health professionals and learn from the experiences of people in similar situations.

There are currently 9 monthly dementia cafes running in the county, including one aimed for those with young onset dementia (YOD). Current locations are:

- Bromsgrove
- Evesham
- Kidderminster
- Malvern
- Pershore
- Redditch
- Tenbury Wells
- Worcester
- Al's Café (for YOD) – various locations [Kidderminster; Worcester; Redditch]

In 2017/18, there were 2,788 activities undertaken at the Dementia Cafes, serving 283 carers of people with dementia, and 261 people with dementia. The age range of service users (people with dementia and their carers) was predominantly 65+ (Figure 8). The majority of cases were referred either through EIDS, or an internal referral (Table 17).

**Figure 8 Age distribution of dementia café service users**



**Table 17: Sources of referrals to Dementia Cafes, 2017/18**

Referral Source 2017/18	Number
EIDS	154
GP	22
CMHT	19
Other health professional	7

Referral Source 2017/18	Number
Family/friend	70
Self-referral	41
Social worker/care manager	19
VCS	27
Carer	<5
Internal referral	157
Unknown/other	48

**Non-commissioned services**

Several additional services are offered by the Alzheimer's Society which are not commissioned.

- Activity groups
- Dementia advisers
- Dementia Support service - offer information to people who are worried about their memory and ongoing support to people affected by dementia face to face, over the phone or in writing. Available Monday to Friday, 9am to 4:30pm
- Information programme - provide a wide range of expert information for people with dementia, their carers, family, friends and health professionals. Topics include: receiving a diagnosis, types of dementia, emotional and practical support, legal and financial information and choosing a care home. Available Monday to Friday, 9am to 4:30pm.
- Peer support programme – 3 monthly sessions, including one for people with YOD, and another for those with dementia primarily affecting communication.
- Side by Side - the service helps people remain active with the support of a volunteer doing an activity of their choice
- Singing for the Brain - groups are based around the principles of music therapy

Table 18 shows the level of service use for 2017-18.

**Table 18 Summary of Alzheimer's Society non-commissioned service use, 2017-18**

Service type	Number of activities	Number of service users (% of which carers)	Age group (NB several listed age 'unknown')			
			≤64	65-74	75-84	85+
Activity group	1848	52 (31%)	<i>Suppressed</i>	26.9%	38.5%	19.2%
Dementia	2788	544 (52%)	13.4%	25.4%	36.9%	15.4%

Service type	Number of activities	Number of service users (%)	Age group (NB several listed age 'unknown')			
Café						
Dementia support	1516	280 (60%)	9.3%	23.2%	29.6%	12.9%
Information programme	72	22 (100%)	40.9%	<i>Suppressed</i>	<i>Suppressed</i>	Nil
Peer support programme	416	108 (61%)	10.2%	45.4%	8.3%	<i>Suppressed</i>
Side by Side	1367	103 (0%)	<i>Suppressed</i>	14.6%	42.7%	33.0%
Singing for the Brain	1657	244 (45%)	13.9%	19.3%	36.5%	16.4%

A common limitation of all carer support data is the lack of detail with regards to the activity delivered at an individual level. NICE guideline highlights the importance of psychoeducational therapy and skills training, however there are limited details on what sort of support is being delivered to carers.

## Safer Communities

### Definition

People with dementia should have the opportunity to be involved in and make a positive contribution to their community. Their community should support their ongoing independence and help maintain their dignity, to improve the wellbeing of those with dementia.

### Need

Improving dementia awareness and social action in communities is a key part of the government's Dementia 2020 policy(23). This is seen to be mainly facilitated through the Dementia Friends initiative (described below), and four key priorities have been identified within this policy:

- delivering three million additional Dementia Friends by 2020
- developing communities to be Dementia Friendly
- encouraging businesses to be Dementia Friendly
- ensuring national and local Government play a leadership role in increasing public sector dementia awareness

### Current Services

Two widespread initiatives have been pursued nationally to improve the community response to dementia – Dementia Friends, and Dementia Action Alliances.

### Dementia Friends

The Dementia Friends programme, undertaken by the Alzheimer's Society, is a national initiative to change perceptions of dementia, aiming to transform the way communities and individuals think, act and talk about the condition(58).

Dementia Friends are individual who have received training, either face-to-face or via online video, to understand more about life for those with dementia. They are encouraged turn this understanding into actions, such as volunteering for an organisation that helps people with dementia, or staying in touch with someone they know who lives with dementia.

Dementia Friendly Communities focus on improving inclusion and quality of life for people with dementia. The Dementia Friendly Communities Recognition Process enables communities to be publicly recognised for their work towards becoming dementia-friendly.

In Worcestershire, there are currently

- 61 Dementia Friends Champions
- 5,397 Dementia Friends
- 1,616 Dementia Digital Friends

### Dementia Action Alliances

A local Dementia Action Alliance (DAA) is a group of people representing different sectors within an area who have come together to make their local community dementia-friendly. Local DAAs provide a structure for local communities to subsequently become officially recognised as dementia friendly communities.

In Worcestershire, there are currently 8 DAAs. Table 19 shows the location of the DAAs and their membership.

**Table 19 Dementia Action Alliances in Worcestershire (59)**

<b>Dementia Action Alliance</b>	<b>Membership</b>
Evesham	Abbey Medical Practice; Age UK Herefordshire & Worcestershire; All Saints Church Evesham; Alzheimer's Society; Barclays Bank, Evesham; Care UK - Ambleside Care Home; Cartridge World; Evesham & District Older People's Forum; Evesham Community Hospital; Evesham Library; Evesham Town Council; Evesham Volunteer Centre; Hereford & Worcester Fire and Rescue Service; imaGine Evesham; James Osborne Optometrists, a trading name of HR Optics Ltd; Merstow Green Funeral Home; Merstow Green Medical Practice; Pebworth First and Blackminster Middle Schools Federation; Religious Society of Friends (Evesham Local Meeting); Richmond Care Villages; Rooftop Housing Group; TechSmart Training CIC; Tesco Evesham; The Gatsby Emporium Ltd; The Rotary Club of Evesham; Warwickshire Police and West Mercia Police; Worcestershire Association of Carers; Worcestershire Telecare; Wychavon Leisure
Kidderminster	Able Access UK Ltd; Age UK Bromsgrove, Redditch and Wyre Forest; Age UK Herefordshire & Worcestershire; Alzheimer's Society; Aylmer Lodge Cookley Partnership; Bewdley library; Care and Support 24; Care UK, Brook Court; Hereford & Worcester Fire and Rescue Service; Home

Dementia Action Alliance	Membership
	Instead Senior Care, Kidderminster; KEMP Hospice; Kidderminster Harriers Football Club; Kidderminster Library; Kidderminster Town Council; Living With Dementia; Museum of Carpet; NHS Wyre Forest CCG; Sainsbury's Kidderminster; Simply Limitless Wellbeing Centre; Stourport Library; TechSmart Training CIC; Tesco Kidderminster; The Gatsby Emporium Ltd; The Key Safe Company; The Swan Shopping Centre; Triangle Day Care Kidderminster; Warwickshire Police and West Mercia Police; Worcestershire Association of Carers; Worcestershire Telecare; Wyre Forest District Council; Wyre Forest Leisure Centre/Places For People Leisure; Wyre Forest Reaching Out
Malvern	Age UK Herefordshire & Worcestershire; Alzheimer's Society; Audley Care Malvern; English Symphony Orchestra; Friends of the Elderly; Home Instead Senior Care Worcester; Malvern Youth and Community Trust (The Cube); Perry Manor Care Home ;TechSmart Training CIC; Tenbury library; The Orchestra of The Swan; Triangle Community Services; Triangle Day Care Malvern; Warwickshire Police and West Mercia Police; Worcestershire Acute Hospitals NHS Trust; Worcestershire Association of Carers; Worcestershire County Council; Worcestershire Telecare
Ombersley	Alzheimer's Society; Checketts Fine Foods ;Kitchens By Design; Lee Strathy; Ombersley and Doverdale Parish Council; Ombersley Bakery and Bed & Breakfast; Ombersley Endowed First School; Ombersley Medical Centre; Ombersley Memorial Hall; St Andrew's Church, Ombersley; Sytchampton Village Hall; TechSmart Training CIC; The Cross Keys of Ombersley; The Key Safe Company ; The Royal British Legion (Ombersley Branch); Thursfields Solicitors; Warwickshire Police and West Mercia Police; Worcestershire Association of Carers; Worcestershire Telecare
Redditch	Age UK Bromsgrove, Redditch and Wyre Forest; Age UK Herefordshire & Worcestershire; Alzheimer's Society; Artrix Arts Centre; Bromsgrove and Redditch Network (BARN); Bromsgrove District Council; Bromsgrove District Housing Trust; Bromsgrove Methodist Church Centre; Bromsgrove, Rubery and Catshill Libraries; Care UK - Ambleside Care Home; Chandler Court, Care UK; Hereford & Worcester Fire and Rescue Service; Home Instead Senior Care Redditch and Bromsgrove; Living With Dementia; Lloyds Bank Bromsgrove; Lloyds Bank Redditch; Lorita's Bakehouse; Redditch Borough Council; TechSmart Training CIC; The Gatsby Emporium Ltd; The Orchestra of The Swan; Valuing Individual People Ltd; Warwickshire Police and West Mercia Police; Worcestershire Acute Hospitals NHS Trust; Worcestershire Association of Carers; Worcestershire County Council; Worcestershire Telecare; Wyre Forest Leisure Centre/Places For People Leisure
Stourport-on-Severn	Stourport Library; Thursfields Solicitors
Wolverley & Cookley	Aylmer Lodge Cookley Partnership; St Peters Cookley; TechSmart Training CIC; Wolverley and Cookley Parish Council
Worcester	Age UK Herefordshire & Worcestershire; Association for Dementia Studies; Christopher Whitehead Language College and Sixth Form; Freedom Leisure - Active Communities Worcester; Lyppard Hub; Marks and Spencer, Worcester; NatWest, Worcester; Perry Manor Care Home;

Dementia Action Alliance	Membership
	S.T.A.R.S Day Centre; St Johns Library; TechSmart Training CIC; The Gatsby Emporium Ltd; The Hive Library; The Key Safe Company ; Vamos Theatre; Warndon Library / Fairfield Centre; Worcester CAB & WHABAC; Worcester City Council; Worcester Tourist Information Centre; Worcester Warriors; Worcestershire Association of Carers; Worcestershire County Council; Worcestershire Health and Care NHS Trust

**Recommendations**

- 23. Assess usage of respite care beds (e.g. days occupied, waiting lists) in addition to comparison to services in other regions
- 24. Explore the expressed need for respite care further with carer groups (see recommendation 28)
- 25. Introduce a recording of primary diagnosis on Carer Assessment databases. This should be included within the service specification for current or future providers of Carer Assessments
- 26. Ensure commissioned carer support services are evidence-based, and service monitoring captures the delivered individual activity
- 27. Continue to increase carer' uptake and knowledge of Worcestershire Association of Carers. Explore initiatives to promote uptake of carer support and make communities (including work environments) more carer-friendly
- 28. Consider a carers needs assessment to inform future commissioning of services
- 29. Consider alternative and innovative approaches, in partnership with commissioners and local interest groups (e.g. Worcestershire Association of Carers), to encourage uptake and referrals to their services from a broader spectrum of the population
- 30. Partners involved in the Dementia Friends initiative should work closely with local partners to improve uptake and engagement with Dementia Friends, to ensure everyone living with dementia in Worcestershire is in a supporting environment. This could involve a focussed roll out to areas with particularly lower numbers
- 31. Dementia Action Alliances or Dementia Friendly Communities should be promoted, particularly in areas currently underserved by these initiatives

# Dying Well

## Palliative care

### Definition

NICE Quality Standard 1 states:

*People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.*

Later stages of dementia is defined as those with moderate to severe dementia.

### Needs

Of those with late-onset (aged  $\geq 65$  years) dementia, 32.1% are estimated to have moderate dementia and 12.5% severe dementia(2). Based on the current estimated prevalence of 8,622 cases (95% confidence interval: 7826 to 9285), this suggests 3,759 people with dementia (diagnosed and undiagnosed) currently have moderate or severe dementia. This number will increase as the overall number of people with dementia increases.

NICE guidance stipulates the following areas which should be addressed to meet the palliative and end of life needs of those with dementia:

- From diagnosis, offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be.
- For people living with dementia who are approaching the end of life, use an anticipatory healthcare planning process, involving the person and their family members or carers (as appropriate) as far as possible. This should address
  - the benefits of planning ahead
  - lasting power of attorney (for health and welfare decisions and property and financial affairs decisions)
  - an advance statement about their wishes, preferences, beliefs and values regarding their future care
  - advance decisions to refuse treatment
  - their preferences for place of care and place of death
- Encourage and support people living with dementia to eat and drink, taking into account their nutritional needs.
- Consider involving a speech and language therapist if there are concerns about a person's safety when eating and drinking.
- Do not routinely use enteral feeding in people living with severe dementia, unless indicated for a potentially reversible comorbidity.
- When thinking about admission to hospital for a person living with severe dementia, carry out an assessment that balances their current medical needs with the additional harms they may face in hospital e.g. disorientation, increased morbidity on discharge, delirium



- When thinking about admission to hospital for a person living with dementia, take into account:
  - any advance care and support plans
  - the value of keeping them in a familiar environment.
- Consider using a structured tool to assess the likes and dislikes, routines and personal history of a person living with dementia

There is also further reference to more general NICE quality standards and guidance on end of life care, the care of dying adults, and decision-making and mental capacity. However, there is currently a lack of evidence to currently determine:

- the most effective models of general and specialist palliative care support to meet the needs of people with advanced dementia
- the most effective interventions to support staff to recognise advanced dementia and develop appropriate escalation/end of life plans to facilitate care to remain at home

These areas therefore require further research before the best-practice services can be identified.

### Current Services

There are no specific dementia-only palliative care services. Specialist palliative care through the Worcestershire Health and Care Trust work closely with linked professionals such as GPs, hospital teams and social workers. The county is served by three teams based at The Princess of Wales Community Hospital Bromsgrove (North East of the county); KEMP Hospice in Kidderminster (North West); and at St Richard’s Hospice (South)(60).

## Preferred Place of Death

**Table 20: Proportions of deaths of people registered with dementia in different places, from PHE Fingertips(24) – 2016 mortality data.**

	Death in usual place of residence	Death in hospital	Death in care home	Death at home
<b>England</b>	67.9%	30.9%	57.6%	9.7%
<b>West Midlands</b>	64.3%	35.0%	54.3%	9.3%
<b>Worcestershire</b>	74.3%	25.6%	63.5%	9.8%
<b>Highlighted figures are statistically different from national average</b>				
<b>R&amp;B CCG</b>	69.5%	31.0%	60.9%	7.8%
<b>SW CCG</b>	75.1%	24.0%	64.3%	9.7%
<b>Wyre Forest CCG</b>	82.5%	18.4%	66.7%	14.4%

*Highlighted figures are statistically different from national average*

Identifying the preferred place of death as part of advanced care and palliative care planning is considered good practice, in general and for people with dementia(61). There is a lack of

consensus as to whether most people prefer to die at home(62), and therefore identifying an individual's preference is crucial.

It is difficult to identify whether people in Worcestershire died in their preferred place of death.

## End of Life

NICE guidance recommends early discussions with people living with dementia, and their carers as appropriate, to consider advance care plan decisions. This includes end-of-life discussion with regards to treatment escalation, resuscitation decisions and preferred place of death. This is primarily undertaken within the primary care setting.

### Current Services

Data from GP records in Worcestershire provides a snapshot of the current extent of end-of-life planning in primary care. There are also 497 people recorded with a dementia diagnosis in Worcestershire with coding suggesting they have an end of life care plan.

CCG	Patients on the dementia register - AGE 65 or over	Patients on dementia register on the palliative care register	DNAR in place of patient on dementia register
RB CCG	1388	191 ( 13.8%)	453 (32.6%)
SW CCG	2483	401 (16.1%)	977 (39.3%)
WF CCG	1019	325 ( 31.9%)	404 (39.6%)
Grand Total	4890	917	1834

This data does not show how many people registered with a diagnosis of dementia have had a discussion with regards to end of life care planning.

### Recommendations

32. Conduct audit processes to monitor

- a) How many people living with dementia have a preference of place of death recorded
- b) How many people with dementia die in their preferred place of death
- c) Whether discussions around end of life have occurred, and the results of these are recorded, enacted and reviewed accordingly

This could benefit from working with wider Worcestershire palliative care team network

# Young Onset Dementia

## Definition

Young onset dementia is defined as the onset of dementia symptoms before the age of 65. At least 40,000 people in the UK are estimated to be living with young onset dementia(2).

## Need

Based on most recent population estimates(63) and age- and sex-specific dementia prevalence rates(2), there are currently an estimated 432 people with early onset dementia aged 30-64. If current age- and sex-specific prevalence remains stable, the number of people with young onset dementia in Worcestershire is likely to increase slightly to 491 by 2028, but reduce to 412 by 2038 based on current population projections(64).

There are a broad range of consequences particular to the earlier onset of dementia. These include loss of employment and associated income and status, reduced ability to care for dependents, and stigma from being diagnosed with a condition associated with the elderly(47). Carers of people with young onset dementia are most commonly spouses of a similar age, and therefore may experience challenges maintaining employment or other responsibilities.

NICE guidance does not explicitly state any separate recommendations for addressing the needs of those with young onset dementia exclusively. This was predominantly due to the lack of robust evidence specifically for this subgroup. However, modifications to general recommendations were made to ensure appropriate cover of the needs of people with young onset dementia were met. In particular, the importance of providing information that explains the person’s rights and needs for reasonable adjustments if they are in work or looking for work was highlighted.

## Current Services

### Access to Services

As of September 2017, there were 174 people registered on the young onset dementia database held by the Worcestershire Health and Care NHS Trust. This is substantially fewer than the anticipated 432 cases in the county. Table 21 summarises the distribution of diagnosing sources for those on the database.

**Table 21 Sources of diagnosis for those with young onset dementia on the WHCT database**

Team/Service Giving Diagnosis	Total Diagnosed
Early Intervention Dementia Service (EIDS)	142
Older Adult Community Mental Health Team (OACMHT)	11
Other (including Out of County)	6
Unknown	15

Team/Service Giving Diagnosis	Total Diagnosed
TOTAL	174

It is felt to be unlikely that those with a diagnosis of young onset dementia would be accessing services if they were not on this database, as it acts as a 'gateway' to guide and direct to other services. This suggests that there are a substantial number who are not using these services. The vast majority on the database are diagnosed within EIDS. Whilst this may reflect where the majority are diagnosed, it suggests that greater awareness of services for early onset dementia may be beneficial in other diagnosing departments (eg. Neurology, CMHT).

### Connected (Onside) advocacy

Connected advocacy is provided by Onside, and is specifically provided for those with early onset dementia. The mentors provide support to enable people who have early onset dementia to enjoy a range of activities and interests. The support is tailored to meet individual needs, choices and circumstances. Mentors work one to one with people with the aim of stimulating and maintaining their skills and interests, enabling them to engage with their local community and develop social networks.

Collated service data is coded for those with cognitive impairment or dementia. The number of cases assessed by Connected has increased in the last three years.

	2015 16	2016 17	2017 2018
Referrals	20	14	44
Age range	37-64	50-64	26-63
Proportion female	55%	64%	39%
Referral sources (% total)	<b>Social services: 65%</b> <b>Other: 35%</b>	<b>Health professional 43%</b> <b>Social services 36%</b>	<b>Social service 61%</b> <b>Psychiatric ward:18%</b> <b>Health professional/carer: 18%</b>

The numbers of service users is small, therefore interpretation of service data is difficult. Nevertheless, there appears to be a consistently larger proportion of people referred from Wyre Forest in comparison to other areas. Referrals tend to be made by those working in social services, which reflects the most likely professionals who would encounter and identify requirements for advocacy for people with young onset dementia. There are very few self-referrals for Connected services.

## Connection Point

This is a monthly evening meeting for younger people living with dementia and their families. It is a service which offers education and information, with a guest speaker attending to talk about varied topics (for example Lasting Power of Attorney), as well as creativity-based activity session. On alternative evenings, there is an opportunity for any family carers to attend the Family Voice Meeting for support, discussion and to have an influence on local developments. The local Admiral Nursing Service and Worcestershire Association of Carers support with this meeting.

Connection Point is jointly run by Alzheimer's Society and Worcestershire Health and Care NHS Trust – with staff from both organisations supporting. Colleagues from Onside Advocacy and local Dementia Advice Service (Age UK Herefordshire and Worcestershire) also attend. Transport can be arranged to aid attendance.

## Al's cafés

This is a monthly, countywide support group for younger people diagnosed with a dementia before the age of 65, their family, friends and carers, which aims to provide information on understanding dementia, what help is available, what families and individuals can do themselves to learn to live with a dementia illness, as well as providing a social environment for people to meet together. The group is supported by professionals from the Older Adults Mental Health Services of the Worcestershire Mental Health Partnership Trust and Admiral Nursing.

Referrals to the service can be made by any professional from the Older Adult Mental Health Services, GPs, or social services staff via the CMHT.

## Worcestershire Works Well

Worcestershire Works Well is a partnership incorporating Worcestershire County Council, Worcestershire Regulatory Services, Herefordshire & Worcestershire Chamber of Commerce, Wellness Works and the Sports Partnership Herefordshire & Worcestershire. It is a free accreditation scheme designed to support businesses to improve the health and well-being of their employees. This may include ongoing workplace health promotion, raising awareness of particular health issues and supporting employees to make healthier lifestyle choices.

Whilst there are not specific accreditation factors with regards to dementia, the programmes does incorporate dementia awareness into the scheme through the reps who provided one-to-one support to businesses, and events such as presentations from the Alzheimer's Society. Furthermore, some Worcestershire Works Well businesses have undertaken Dementia Friends training within their organisations.

## Recommendations

33. Consider dedicated oversight specifically for YOD:

- To maintain and monitor the YOD database
- To consider where people with YOD will be diagnosed, and assess whether the expected number are being registered through such services
- To advocate for YOD-specific issues (e.g. support in the work place) across the county

- To help drive improvement in recognition and diagnosis of YOD, and awareness of YOD-specific services amongst all health and social care professionals
  - To develop a programme for the identification and early intervention of young onset dementia. In addition to diagnosis, the programme could incorporate help to sustain employment and have close links to YOD-specific services
34. Consider reconciliation of YOD databases held by the WHCT, with dementia register in those aged  $\leq 65$  on GP records
35. Conduct further work to specifically understand the reasons for substantially lower levels of registered people with young onset dementia compared to the estimated. Possible explanations: data error, lack of referral for diagnosis, lack of referral to support services, less public awareness of symptoms causing reduced diagnosis-seeking
36. Increase awareness of YOD advocacy services throughout the county to aid uptake of services, in particular outside Wyre Forest, and raise awareness in other professionals and to people with young onset dementia

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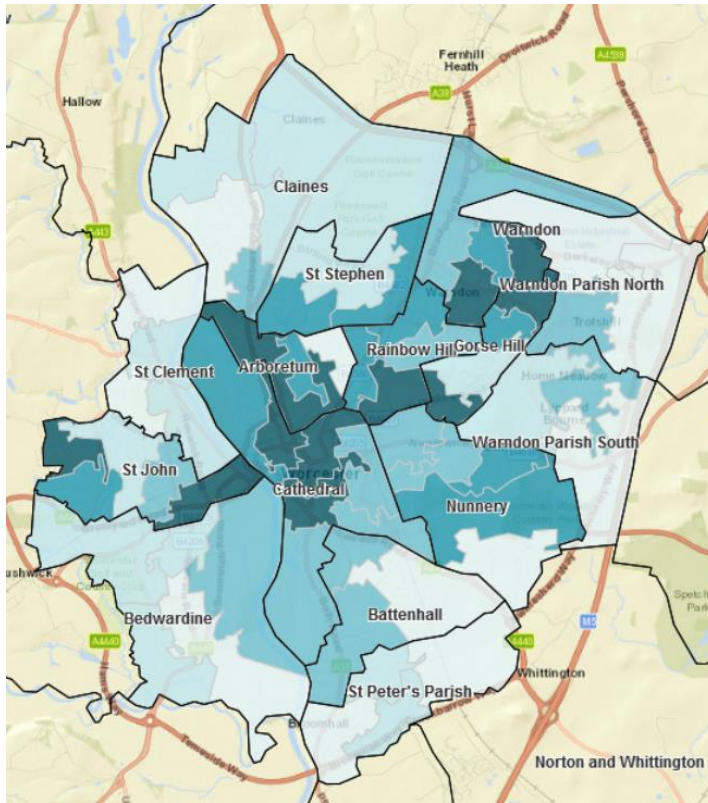
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# Appendix

## Loneliness 'heat maps' as described by Age UK<sup>2</sup>

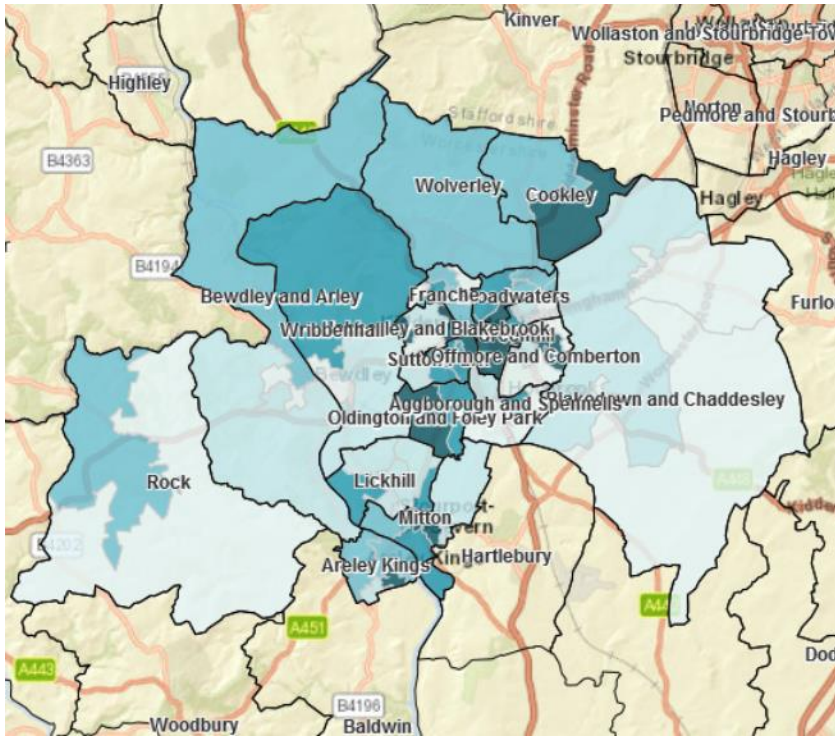
### Worcester



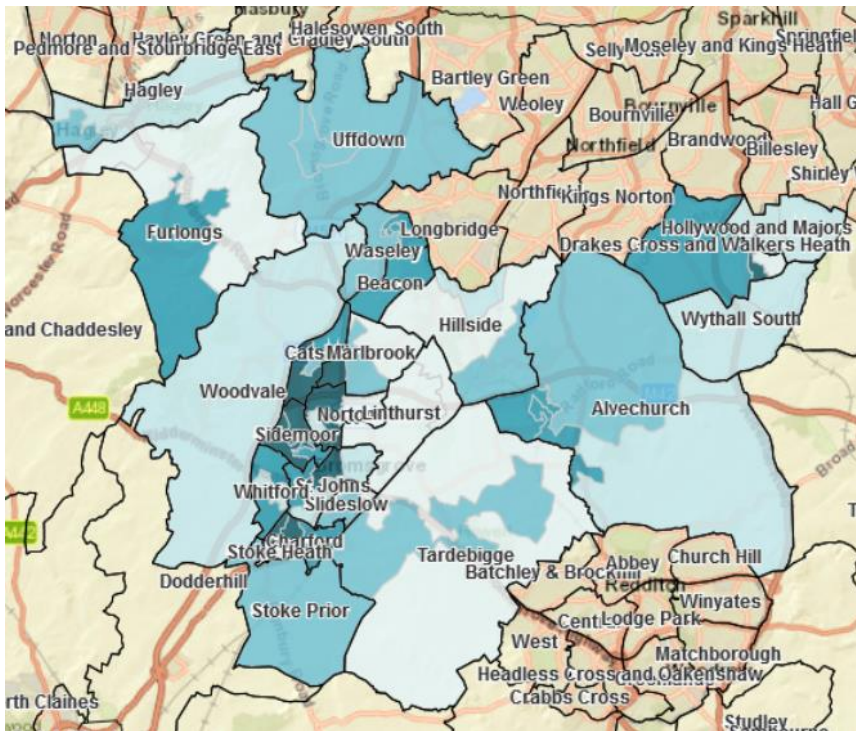
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<sup>2</sup> (<https://www.ageuk.org.uk/our-impact/policy-research/loneliness-research-and-resources/loneliness-maps/>)

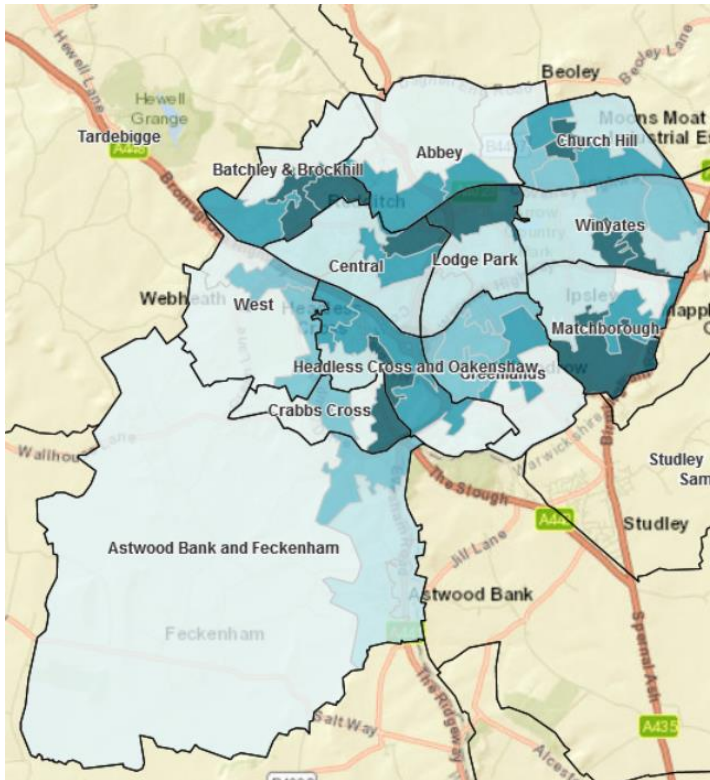
### Wyre Forest



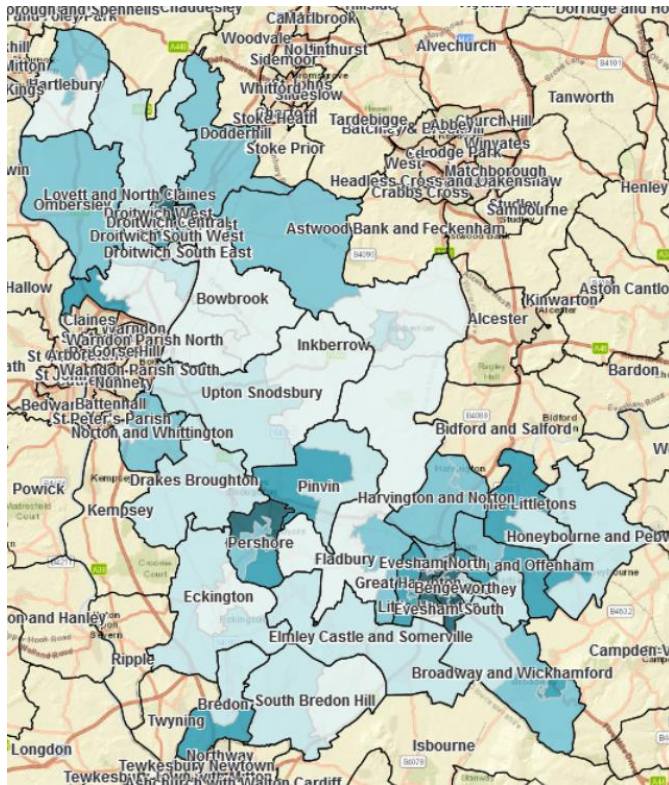
### Bromsgrove



## Redditch



## Wychavon



### Malvern Hills

