



**WIRRAL  
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# **JSNA: Dementia**

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**July 2019**

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## JSNA: Dementia

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### Background to JSNA – Joint Strategic Needs Assessment

#### **What is a JSNA?**

A Joint Strategic Needs Assessment, better known as a JSNA, is intended to be a systematic review of the health and wellbeing needs of the local population, informing local priorities, policies and strategies that in turn informs local commissioning priorities that will improve health and wellbeing outcomes and reduce inequalities throughout the Borough.

#### **Who is involved?**

Information from Council, NHS and other partners is collected and collated to inform the JSNA and this reflects the important role that all organisations and sectors (statutory, voluntary, community and faith) have in improving the health and wellbeing of Wirral's residents.

#### **About this document**

This JSNA section looks to contain the most relevant information on the topic and provides an overview of those related key aspects

#### **How can you help?**

If you have ideas or any suggestions about these issues or topics then please email us at [wirralintelligenceservice@wirral.gov.uk](mailto:wirralintelligenceservice@wirral.gov.uk) or go to <https://www.wirralintelligenceservice.org/>

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## Content overview

<b>Abstract</b>	This report provides an overview of the current local and national position related to dementia given the most available data and information; looking at key risks to developing dementia alongside the current and future local work to alleviate any impacts.
<b>Intended or potential audience</b>	<p><b>External</b></p> <ul style="list-style-type: none"> <li>• Wirral Dementia Strategy Board</li> <li>• Wirral Health and Care Commissioning Members</li> </ul> <p><b>Internal</b></p> <ul style="list-style-type: none"> <li>• Range of Senior Leadership Teams</li> <li>• Colleagues in Integrated Commissioning Hub (ICH) and other teams</li> <li>• Colleagues and those leading on work to alleviate impacts of dementia</li> </ul>
<b>Links with other topic areas</b>	<ul style="list-style-type: none"> <li>• <a href="#">Carers</a></li> <li>• <a href="#">Long-term Conditions</a></li> <li>• <a href="#">Older People</a></li> <li>• <a href="#">Mental Health</a></li> <li>• <a href="#">Adult Obesity</a></li> <li>• <a href="#">Alcohol</a></li> <li>• <a href="#">Black Asian and Minority Ethnic residents</a></li> <li>• <a href="#">Cardiovascular Disease</a></li> <li>• <a href="#">Diabetes</a></li> <li>• <a href="#">Hypertension (High Blood Pressure)</a></li> <li>• <a href="#">Learning Disabilities and Autism</a></li> <li>• <a href="#">Mental Health</a></li> <li>• <a href="#">People with Long Term Conditions</a></li> <li>• <a href="#">Sexual Health</a></li> <li>• <a href="#">Sight Loss - Adults and Sight Loss – Children and Young People</a></li> <li>• <a href="#">Social Isolation and Loneliness</a></li> <li>• <a href="#">Tobacco (Smoking)</a></li> </ul>

## Acknowledgements

We would like to thank the members of the Dementia Strategy Group for their support and involvement in the development of this updated and refreshed Dementia JSNA Chapter.

## Key findings

- As of January 2019, there are currently 3,073 people aged 65+ who have a recorded diagnosis of dementia in Wirral
- Overall, projections estimate that the total number of people with dementia in Wirral will increase from 5,086 in 2019 to 7,135 in 2035
- Dementia rates are expected to increase in Wirral by 40.7% between 2019 and 2035. This is lower than the projected England increase of 50.2% over the same period
- The sharpest increase in dementia prevalence rates are estimated to be in the older populations. For example, those aged 90+ are estimated to see a 53% increase between 2019 and 2035
- The prevalence of early onset dementia (aged under 65) is estimated to decrease by 12% between 2019 and 2035 in Wirral. For England, this figure is an increase of less than 2%
- Wirral has an estimated diagnosis rate of 68.6% for those aged 65+ for the latest quarter of 2018/19 - this is better than the national rate of 68.0%
- At both a Wirral and England level, it is estimated that early-onset dementia is more common in males (58.2% for Wirral and 58.8% for England)
- For late-onset dementia, however, it is more common in females (64.3% for Wirral and 63.4% for England)
- The ratio of inpatient service use to recorded dementia diagnoses increased between 2015/16 and 2017/18 for Wirral, Cheshire and Merseyside and England
- The largest proportion of dementia-related inpatient admissions typically lasted less than 7 days (40.1%) between 2013/14 and 2017/18
- The proportion of dementia-related short stay emergency admissions between 2014/15 to 2016/17 in Wirral have increased
- Just over 80% of inpatient admissions came through Accident & Emergency between 2013/14 and 2017/18
- The most common primary diagnosis for dementia-related conditions was pneumonia (9.0%) following by disorders of the urinary system (7.2%) and septicaemia (5.3%)
- The actual costs involved in prescribing dementia drugs in Wirral have decreased by 50.1% from 2014/15 to 2018/19
- Services provided to those with a recorded condition of dementia, aged 65+, by the Wirral Department of Adult Social Services (DASS) increased by 68% between 2013/14 and 2017/18
- The largest single services provision was “Assistive Technology” (18.92%). However, an aggregation of residential services showed that 1 in 4 (24.52%) received support outside of the home environment
- Claughton ward had the highest rate of service users with a recorded condition of dementia as at January 2019
- Dementia-related deaths occurring at home have repeatedly increased in Wirral and in England. On the other hand, dementia-related deaths occurring at hospital have repeatedly decreased since 2011/12
- The Alzheimer’s Society estimates that those with Down’s Syndrome have a 50% chance of developing dementia after they reach the age of 60
- There is expected growth in the number of people from BAME communities who will develop dementia as the BAME population ages

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## What do we know?

## Why is this important?

### What is Dementia?

The [World Health Organisation](#) describes dementia as a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. Progression can vary from person to person and everyone will experience dementia differently. Dementia can affect memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgement, mood and behaviour.

Dementia is one of the major causes of disability and dependency among older people worldwide. This is the case not only for the people who have the condition, but also for their carers and families. There is often a lack of awareness and understanding of dementia, resulting in stigmatization and barriers to diagnosis and care. The impact of dementia on carers, family and societies can be physical, psychological, social and economic.

Living with dementia is a challenge, but it is possible for people with dementia to experience positive relationships and live well with dementia. Communication can help to enable positive feelings such as contributing to their communities through local support groups and sharing experiences with others.

### The scale of the challenge

The latest dementia prevalence estimates published by the [Alzheimer’s Society: Dementia UK: Update](#) (2014) estimates that 1 in every 79 people (1.3%) in the UK has dementia, with 1 in 14 of the population aged 65 and above (7.1%). Dementia is not just a national issue; it is a global issue. Alzheimer’s Society and Alzheimer’s Research UK state that 50 million people are living with dementia worldwide, with too many of those struggling alone, feeling as though their world has been turned upside down and often facing prejudice or misunderstanding. By 2050, the number of people living with dementia worldwide is projected to rise to almost 150 million ([HM Government \(2016\)](#)). To raise awareness of the enormity of the dementia challenge facing us, this year (2019), the official charity of the London Marathon was [Dementia Revolution](#) – a joint partnership between Alzheimer’s Society and Alzheimer’s Research UK.



Source: [Public Health England](#)

Currently, there are an estimated 21 million people in England who have a close friend or family member living with dementia. Directly or indirectly, it will soon affect every one of us.

Dementia is also the most feared health condition for people over the age of 55 according to a survey by [Alzheimer's Research UK](#). More feared than any other major disease, including cancer and diabetes.

## Types of dementia

### Age-related dementia

Dementia is usually categorised as 'early onset dementia' if the individual affected is under the age of 65 years old, with dementia occurring above this age deemed 'late onset dementia'.

#### Early Onset Dementia

Early onset dementia, also referred to as 'young onset' or 'working age' dementia, refers to any type of dementia that occurs in an individual under the age of 65. There is no minimum age that somebody can start to exhibit symptoms of dementia with the condition developing at any age. As with dementia generally, there can be conflicting information about the prevalence of young onset dementia. Young Dementia UK suggest that the low levels of awareness and the difficulties of diagnosing the condition at working-age mean popularly used statistics are likely to be inaccurate and do not reflect the true number of people who are affected. Please see Figures 2 and 4 for the breakdown of young onset dementia by Wirral and England.

Prevalence figures for young onset dementia can also be found here:  
<https://www.youngdementiauk.org/young-onset-dementia-facts-figures>

#### Late Onset Dementia

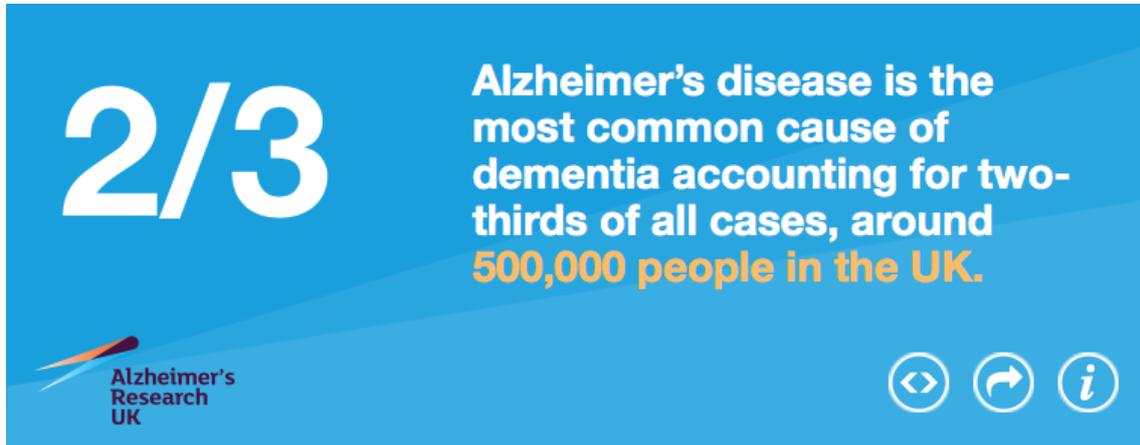
Dementia that affects people older than 65 years of age is known as 'late onset'. Please see Figures 1 and 3 for the breakdown of late onset dementia by Wirral and England.

There are over 100 different types of dementia known to exist. Information of the most commonly recognised types of dementia can be found on the following pages – including Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia and Frontotemporal Dementia. When individuals show symptoms across multiple dementia types, this is known as 'mixed dementia'.

## Most recognised types of dementia

### Alzheimer's Disease

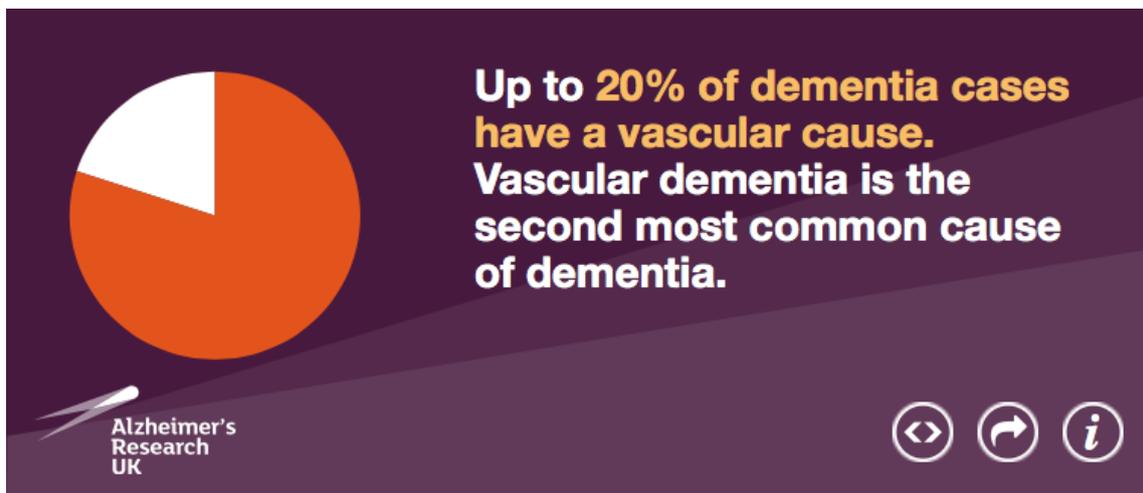
Alzheimer's disease is by far the most well-known and common type of dementia. The common symptoms include memory loss, confusion, difficulty communicating, anxiousness and paranoia. The mechanisms behind Alzheimer's disease developing aren't well understood with a range of different theories behind its emergence. The most distinguishing feature of Alzheimer's disease, however, is the build-up of amyloid plaques and tau tangles in the brain. It's widely believed that these changes to the brain are behind the disease.



Source: [Alzheimer's Research UK](#)

### Vascular Dementia

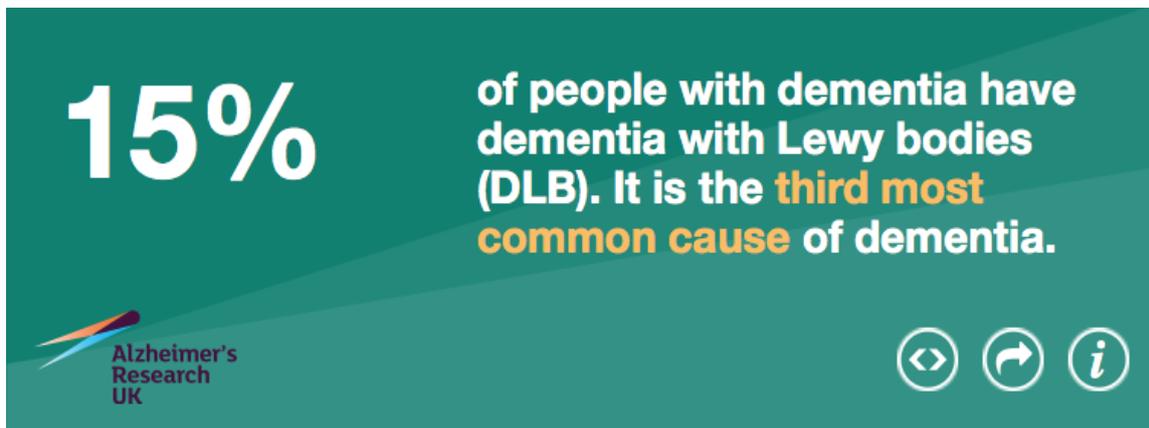
Vascular dementia, also known as “multi-infarct dementia” or “post-stroke dementia”, is the second most common cause of dementia. The symptoms include memory loss, impaired judgment, decreased ability to plan and loss of motivation. The main cause is considered to be a reduced blood supply to the brain following a stroke. However, diabetes, heart disease and high cholesterol can also all contribute to the onset of vascular dementia.



Source: [Alzheimer's Research UK](#)

### Lewy Body Dementia

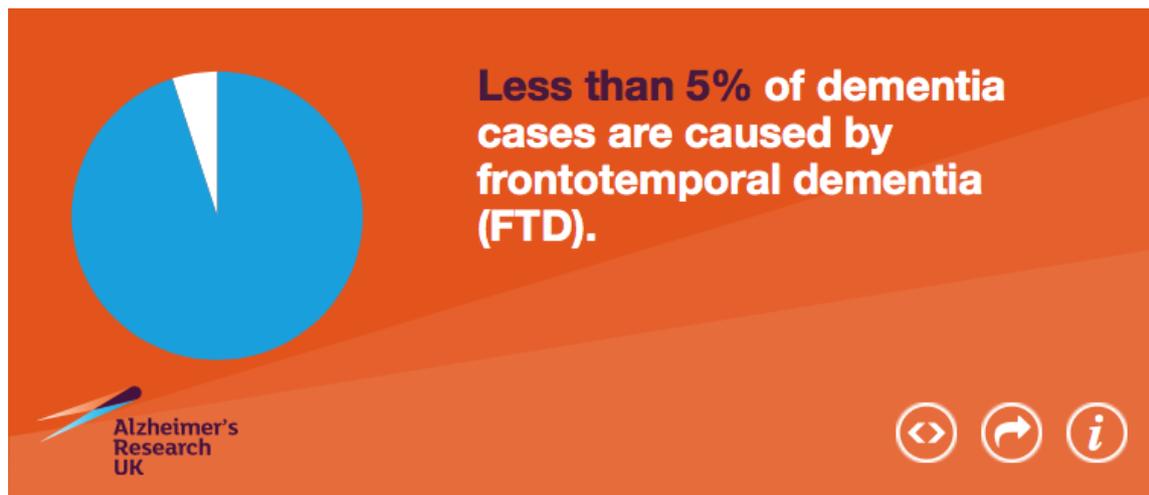
Lewy body dementia is the third most common cause of dementia; also known as “cortical Lewy body disease” or “diffuse Lewy body disease”. It is closely linked with the development of Parkinson's disease. Symptoms can include sleep problems, memory loss, hallucinations and frequent swings in alertness. Lewy bodies are abnormal proteins that somehow appear in nerve cells in the brain, impairing its function. The exact causes as to why Lewy bodies appear are not yet fully understood.



Source: [Alzheimer's Research UK](#)

### Frontotemporal Dementia

Frontotemporal dementia is rare, but believed to be the fourth most common type of dementia. This type of dementia is also known as “frontal lobe dementia” or “Pick’s disease”. Unlike the types of dementia noted above, frontotemporal dementia is marked more by behavioral and emotional changes than by cognitive impairment. In fact, memory is often preserved in people with frontotemporal dementia until much later stages. Symptoms include decreased inhibition (frequently leading to inappropriate behaviour), apathy and loss of motivation, decreased empathy, repetition of compulsive behaviours, as well as anxiety and depression. Frontotemporal dementia occurs when the frontal or temporal lobes of the brain are damaged or shrink.



Source: [Alzheimer's Research UK](#)

### LATE Dementia

Not to be confused with ‘late-onset’ dementia, LATE (or limbic-predominant age-related TDP-43 encephalopathy) dementia is a recently discovered type of dementia (April 2019). This [BBC news article](#) explains how the characteristics of LATE are very similar to that of Alzheimer’s disease making it very difficult to diagnose. This discovery also helps to explain why the development of a cure has been so problematic for scientists. The full study can be found [here](#).

### Other causes of Dementia

Just about any condition that causes brain or nerve cell damage can also cause dementia. For example, people with Parkinson’s disease will often exhibit dementia in the later stages of their illness. [Huntington’s disease](#), [Creutzfeldt-Jacob disease](#) and [alcoholism](#) may all lead to cognitive impairment.

## Who is at risk?

### Older People

The [World Health Organisation \(WHO\) reports](#) that the strongest known risk factor for dementia is age: the older you get the more likely you are to develop dementia. [Alzheimer's Society interactive tool](#) suggests that 6 out of 100 people aged 75-79 have dementia.

Dementia is not an inevitable part of ageing, however, but we do know that the risk of developing dementia increases with age - and as explored earlier in the document, dementia can also be young onset (symptoms developed before 65 years of age). [Alzheimer's Society Factsheet](#) explains that ageing as a risk factor for dementia may be due to factors associated with ageing, such as:

- Changes to nerve cells, DNA and cell structure
- Weakening of the body's natural repair systems
- Higher blood pressure
- Changes to the immune system
- Loss of sex hormones after mid-life changes
- Increased risk of cardiovascular disease

### Younger People

[Alzheimer's Society](#) suggests that there are at least 40,000 people under 65 in the UK who have dementia. This group of people may face increased stigma and difficulties, particularly if they are carers for young children and are in employment. Figure 4 shows that prevalence estimates for Wirral suggest there are 93 residents with dementia under the age of 65.

### Genetics (contributory factor)

Evidence provided by [NHS England](#), implies that certain genetic factors are involved with some more unusual forms of dementia. [Alzheimer's Research UK report, 'Genes and Dementia'](#), explains that 'risk genes' and 'faulty genes' could be risk factors in developing dementia. Risk genes are variations in genes that may alter your risk of diseases which may also increase the likelihood of getting dementia. Faulty genes are genes that we inherit from a parent that do not work properly which may affect how your body functions and may cause you to develop certain diseases. Some rare forms of Alzheimer's and frontotemporal dementia can all be caused by faulty genes.

### Gender

[Dementia statistics by Alzheimer's Research UK](#) reveals that only 35% of people living with dementia are men compared to 65% women. Women are more likely to develop dementia than men. One of the reasons for this is likely to be due to women's longer life expectancy. While some studies have suggested that other factors may affect the number of men and women with dementia, there is no firm evidence that women are more likely than men to develop dementia at any given age. Women are more likely to be dementia carers than men and this often leaves them feeling isolated and depressed – a risk factor in itself for dementia.

### Ethnicity

The [Social Care Institute for Excellence \(SCIE\) reports](#) that there are more older Black, Asian and Minority Ethnic (BAME) people living with dementia in the UK compared to other ethnicities, partly because of the vascular risk factors found in Afro-Caribbean and South Asian UK populations for illnesses such as hypertension, high blood pressure, diabetes, stroke and heart disease. The SCIE says that these effects may be due to a mixture of differences between ethnicities such as diet, smoking, exercise and genes. They also report that other ethnic groups have a demographically older population, such as Irish and Jewish, where prevalence of dementia is likely to be higher with a link between age and dementia.

The All-Parliamentary Party Group reported in [“Dementia does not discriminate” \(2013\)](#) that there were an estimated 25,000 people with dementia from BAME communities in England and Wales, with projections estimating that this will increase to nearly 50,000 by 2026. Their report also suggests that people from BAME communities are under-represented in dementia services and are less likely to be diagnosed or are diagnosed at a later stage. Reasons for this could be due to communication issues, cultural bias and lack of awareness about the condition.

### **Learning Disabilities**

The prevalence of dementia is four times greater among people with a learning disability according to [Public Health England](#).

### **Down's Syndrome**

Down's syndrome, also known as Down syndrome, is a genetic condition caused by an extra copy of chromosome 21 in cells. This typically causes some level of learning disability and characteristic physical features. Research has also acknowledged that the additional copy of this chromosome contains a gene that produces proteins involved in changes in the brain caused by Alzheimer's, which is why it is believed that those with Down's syndrome have a higher risk of developing dementia.

It is currently estimated that there are around 21,199 adults in England and 115 adults in Wirral with Down's Syndrome ([POPPI](#) and [PANSI](#), 2019). The Alzheimer's Society estimate that 1 in 50 people (or 2%) with Down's Syndrome develop dementia in their 30s. This rate rises to more than 50% for people with Down's Syndrome who live into their 60s, compared to the estimate of 1.3% for people aged 60-69 without a learning disability.

### **Sexual identity**

This is an area that is only beginning to be addressed in dementia research, but studies have shown that 41% of older lesbian, gay and bisexual people live alone compared to 28% of heterosexual people; loneliness and social isolation being known risk factors for dementia. Little is known about the risk of dementia among the transgender community.

### **Religion or belief**

Some culturally specific conceptualisations of dementia view the condition as a normal part of ageing or of having a spiritual, psychological or social cause. This has prevented many groups from identifying dementia as a medical issue and ultimately are not accessing support for dementia.

More information can be found via the following link:

<https://publichealthmatters.blog.gov.uk/2016/03/22/health-matters-health-inequalities-and-dementia/>

*Further details on those who are at risk can be found in the supplementary section of this document [here](#) plus other JSNA chapters via the [Wirral Intelligence Service website](#)*

## **What are the risk factors?**

### **Healthy Lifestyles and Behaviours**

[NHS England](#) consider there is no definite way to prevent all dementia types but there is evidence to show that lifestyle changes can help reduce your risk of developing dementia. Research studies have shown that by acting on the risk factors that people are able to change, a reduction in risk of dementia by up to 30% could be achieved. This could be done by exercising regularly and maintaining a healthy weight, eating a healthy balanced diet, keeping alcohol consumption low, stopping smoking and keeping blood pressure at a healthy level.

## Medical conditions and diseases

[Healthline describe various factors](#) that can affect your risk of developing dementia, with pre-existing medical conditions and diseases being among them.

According to the [Alzheimer's Society Factsheet](#), the main health-related risk factors for dementia (especially vascular dementia caused by problems with blood supply to the brain) are:

- type 2 diabetes in mid-life or later,
- high blood pressure in mid-life,
- obesity in mid-life,
- high blood cholesterol levels in mid-life and
- having a cardiovascular disease (which can increase dementia risk by up to two times).

[NHS England](#) consider there is no definite way to prevent all dementia types but there is evidence to show that lifestyle changes can help reduce your risk of developing dementia. They go on to suggest that research studies have shown that by acting on the risk factors that people are able to change, a reduction in risk of dementia by up to 30% could be achieved. This could be done by exercising regularly and maintaining a healthy weight, eating a healthy balanced diet, keeping alcohol consumption low, stopping smoking and keeping blood pressure at a healthy level.

## Mild Cognitive Impairment

Mild Cognitive Impairment (MCI) is an intermediate stage between the mental decline expected through normal ageing and more severe mental decline seen in those with dementia; although not all cases of MCI lead to dementia. MCI is not a specific disease but a collective of symptoms such as mild problems with memory and reasoning. As such there is no readily available data available at a national or local level, however, [Alzheimer's Society \(2014\)](#) estimate that MCI affects between 5-20% of those aged 65 and over. Applying this estimate to Wirral's population indicates that between 3,500 and 14,000 of those aged 65+ in Wirral could have MCI.

## Depression

It is possible that depressive symptoms increase dementia risk due to their effect on stress hormones and hippocampal volume. However, it is not clear whether depression is a cause or a symptom of dementia. It was found to be responsible for 4% of the risk of developing dementia.

## Midlife hearing loss

The relationship between hearing loss and the onset of dementia is new. It is thought that hearing loss may add stress to an already vulnerable brain about the changes that occur. Hearing loss may also increase feelings of social isolation. However, it is also possible that old age could have a role to play in this association. Lancet Commission on Dementia Prevention, Intervention and Care ([LCDPIC, 2018](#)) analysis found that hearing loss could be responsible for 9.1% of the risk of developing dementia.

## Visual impairment

New data from a study published by National Institute for Health Research ([NIHR, 2016](#)) shows that around a third of people with dementia have serious vision problems, such as cataracts or short sightedness, more than the general population of that age. Levels are higher still for people with dementia in care homes where about half have vision problems.

The study also shows that these conditions were treatable; almost half of those found to be visually impaired were provided with prescription glasses to correct visual problems, with around 25% being impaired as a result of cataracts, which could be surgically removed.

A briefing report [Sight, perception and hallucinations in dementia \(Alzheimer's Society, 2016\)](#), suggests that eye conditions that can affect visuo-perception include cataracts, glaucoma, macular degeneration and retinal complications from diabetes. Also, certain medications can cause or contribute to problems with vision as well as specific types of dementia can also damage the visual system and cause visuo-perceptual difficulties.

Further details on those who are at risk can be found in the supplementary section of this document [here](#) plus other JSNA chapters via the [Wirral Intelligence Service website](#)

### **What steps can be taken to reduce the risk of developing dementia?**

The World Alzheimer Report of 2014 - [Dementia and Risk Reduction: An Analysis of Protective and Modifiable Factors](#) - suggests that evidence for possible causal associations with dementia include:

- low education in early life
- hypertension in midlife
- and smoking and diabetes across the life course

The same report also suggests that improved detection and treatment of diabetes and hypertension, and smoking cessation, should be prioritised, including for older adults who are rarely specifically targeted in prevention programs.

Whilst research identifying modifiable risk factors of dementia is in its infancy, primary prevention should focus on areas suggested by current available evidence. These include countering risk factors for:

- vascular disease including diabetes,
- midlife hypertension,
- midlife obesity,
- smoking and
- physical inactivity



Source: [Public Health England](#)

Introducing improved dementia prevention and interventions now will:

- contribute to cost savings across the health and social care system
- support people to live longer and healthier lives
- reduce the risk of developing a number of other long-term physical conditions, such as hypertension and heart disease as well as mental health conditions such as depression
- impact on costs associated with non-communicable diseases such as heart disease or stroke
- transform the future of society

## Dementia and inequalities

### Life risk factors

In October 2016, the [Institute of Health Equity published a report “Inequalities in Mental Health, Cognitive Impairment and Dementia among Older People”](#), which focused on the inequalities throughout the life course that may contribute to the development of poor mental health, including dementia, in later years. Several risks linked to inequalities were identified, including factors such as educational attainment, unemployment, housing conditions and deprivation.

### Social isolation

Although research by the Lancet Commission on Dementia Prevention, Intervention and Care ([LCDPIC, 2018](#)) describes potentially modifiable risk factors, the content further suggests other underpinning inequalities, such as social isolation, can have an impact. The lack of social contact is increasingly thought to be a risk factor for dementia as it also increases the risk of hypertension, heart conditions and depression. However, as with depression, it remains unclear whether social isolation is a result of the development of dementia. It was found to contribute to 2.3% of the risk of developing dementia.

### Socio-economic gradients in risks

There are several dementia risk factors related to socio-economic position such as a lack of physical activity and early year's education. There is also a strong link between cigarette smoking and socio-economic group. Smoking has been identified as the single biggest cause of inequality in death rates between affluent and poor population groups in the UK. Some studies suggest that it can double the risk of developing dementia.

### Low levels of education

Less time in education - specifically, no secondary school education – was considered responsible for 7.5% of the risk of developing dementia. However, and for social isolation, it is important to note that to add up the percentage risk of all these factors, they only account for about 35% of the overall risk of getting dementia. This means about 65% of the risk is still due to factors out of an individual's control, such as ageing and family history.

### Societal barriers

In June 2019 the All-Party Parliamentary Group (APPG) on Dementia published [Hidden no more: dementia and disability](#). The APPG report looked at the societal barriers that prevent people with the condition living independently and provided a framework for action based on disability rights. It made recommendations for local and national government to take action in 6 key areas to improve the lives of people with dementia including: employment, social protection, social care, transport, housing and community life.

*Further details on those who are at risk can be found in the supplementary section of this document [here](#) plus other JSNA chapters via the [Wirral Intelligence Service website](#)*

### Living with dementia

Dementia has a significant impact on an individual's health and quality of life. It can result in a range of health and social problems which can be challenging for the person with dementia, their carers, and health and social care professionals. The prognosis for a person with dementia varies depending on the cause of the dementia and the pattern of symptoms.

As the dementia progresses, people with dementia can experience severe cognitive impairment and memory loss. Psychological and behavioural problems such as depression, disorientation, and aggression may also develop and get worse over time which can be difficult to manage. These 'distressed' behaviours may be exhibited due to pain, anxiety, fear or may be a reaction to external factors such as staff behaviour or poor physical environments. Establishing what is causing the distress and dealing with these issues usually results in being able to better manage distressed behaviours

Research shows that large proportions of people with dementia feel unsupported and do not feel part of their community. They often experience anxiety and depression and three quarters do not feel society is properly equipped to deal with dementia ([Alzheimer's Society, 2012](#)).

While another survey undertaken by the Alzheimer's Society ([Alzheimer's Society, 2013](#)) suggests that progress is being made, with almost two-thirds (61%) of respondents reporting that they were living well with the condition. The report also found that quality of life is still varied for a significant number of people with dementia. The environment, presence of depression, social isolation and loneliness are key drivers for poor quality of life for people with dementia.

In addition to this, as life expectancy increases for people with complex disabilities, carers for these individuals will be caring for longer and may develop dementia themselves; affecting their ability to provide care. Many parent carers are single parents, which is an additional risk factor delaying identification.

### Impact on carers

One in seven carers juggle with work and caring responsibilities; 2.6 million carers give up work in order to care and 2 million have reduced their working hours (["Juggling work and unpaid care", Carers UK 2019](#)). Nationally, provision of unpaid care for those with dementia contributes more in financial terms than contributions from any other agency (45% of the total, with social care second providing 40% ([Kings College London & London School of Economics, 2014](#))).

Hammersmith and Fulham, Kensington and Chelsea and Westminster have produced a brief review of published evidence on the efficacy and effectiveness of interventions for dementia care, management, support and prevention. The review focuses on:

- prevention of dementia
- management and care of people with dementia
- living well with dementia
- dementia friendly communities
- telehealth/telecare for people with dementia
- support for carers

It is also highlighted in the review that carers are often old themselves, more likely to be women, and are likely to be providing a substantial number of hours of support ([JSNA Hammersmith and Fulham, Kensington and Chelsea and Westminster 2015](#)).

Research on carers has found that those providing care are more likely to be in poor health than those not providing care ([Pinguart & Sorensen, 2003](#)). Emotional and mental health problems tend to be more often linked with care giving than physical health problems.

Nationally, carers providing substantial levels of care (27%) are twice as likely to have mental health problems as opposed to those providing a lower level of care (13%). One review suggests that carers of people with dementia have worse health outcomes than other carers ([Pinguart & Sorensen, 2003](#)).

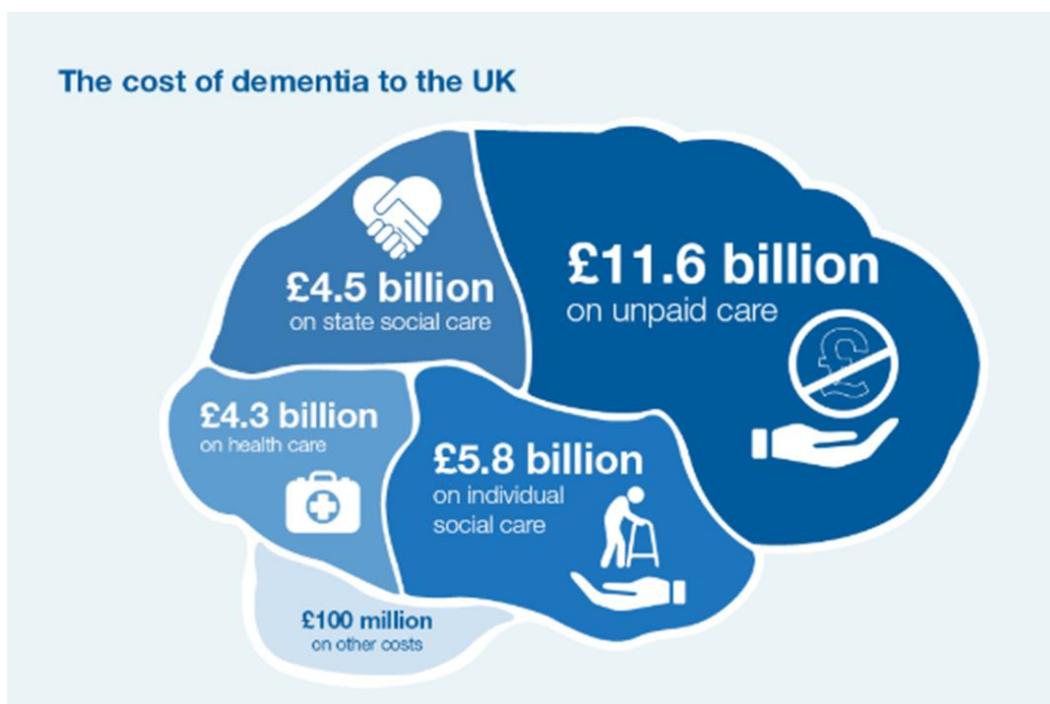
In addition to poorer physical and mental health, carers can often suffer from social deprivation, isolation, fewer opportunities for paid employment or education, or having time to themselves or with friends. For young carers, it can often mean life chances are severely limited.

Caring responsibilities are likely to have a significant impact on carers' quality of life which can be compounded for those looking after somebody with dementia than carers generally.

## Why invest in dementia?

Dementia imposes a huge emotional and financial cost. As the number of people with dementia rises so too will the costs for the health and care system, as well as the individual's families. The estimated total cost of dementia in the UK is £26.3 billion, of which £17.4 billion is paid by people with dementia and their families, by way of unpaid care or private social care. This averages at approximately £32,250 per person per year and is higher than the cost of cancer, heart disease and stroke.

Although, local authorities and NHS organisations are under increasing financial pressure, investment in dementia care is vital in order to ensure appropriate, effective management of the condition (before reaching a crisis point) and to provide support to families and carers in order to maintain their own health and wellbeing.

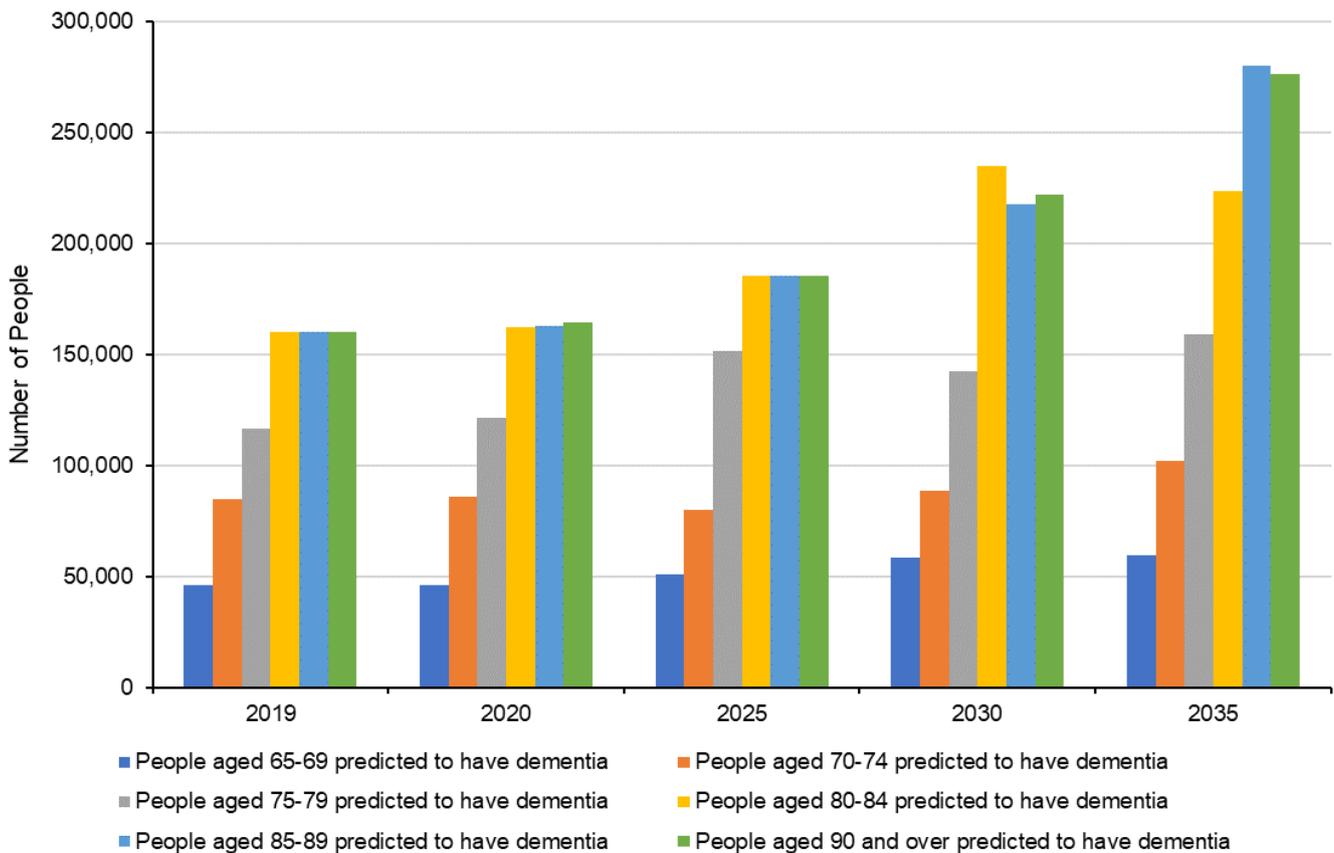


Source: [Public Health England](#), March 2016

### National Prevalence

Figure 1 shows that the number of people with dementia in England is expected to increase between 2019 and 2035, with older age bands likely to see a sharper increase. For example, it is expected that those aged between 65-69 years will increase from 46,402 to 59,874 (an increase of 29%), whereas those aged 90+ will increase from 160,505 to 276,390 (an increase of 72%).

**Figure 1:** Estimated projections of people with late onset dementia, by age group. England, 2019-2035

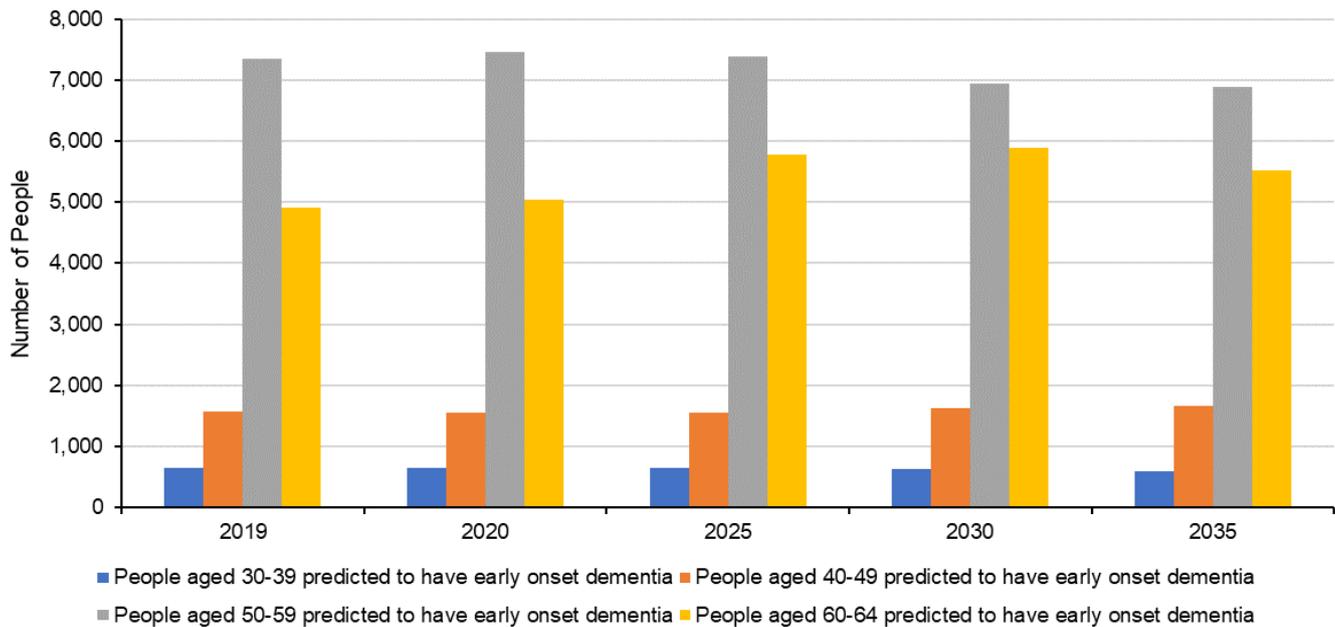


Source: [POPPI](#)

Should this prevalence rate of dementia remain the same, it is estimated that the total number of people aged 65 and over with dementia in England will rise from around 728,671 in 2019 to approximately 1,101,818 in 2035 (an increase of over 51% in 16 years).

Figure 2 shows estimated projections for early onset dementia in England and suggests that this will increase slightly, from 14,483 in 2019 to 14,666 in 2030; an increase of less than 2%.

**Figure 2:** Estimated projections of people with early onset dementia, by age group, England, 2019-2035

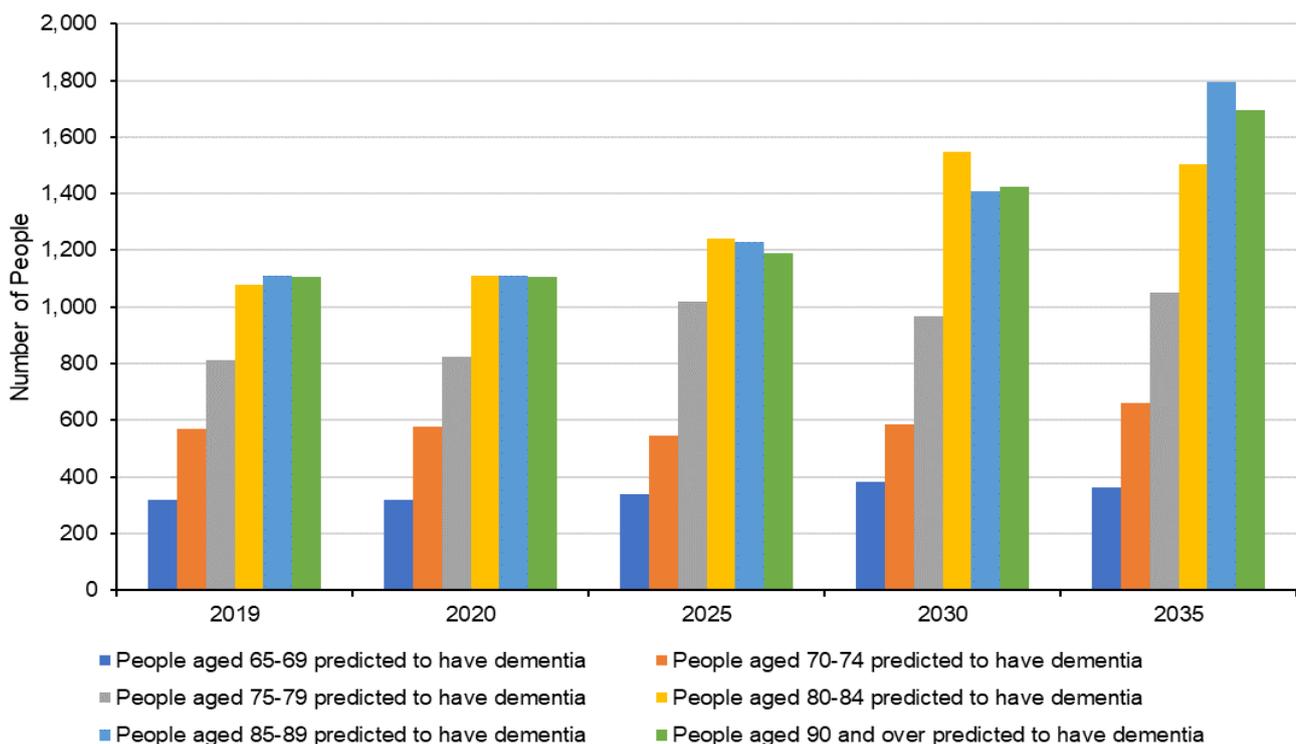


Source: [PANSI](#)

### Local Prevalence

Figure 3 shows that the estimated number of people with late onset dementia in Wirral is expected to increase between 2019 and 2035. Similar to the national projections in Figure 1 above, it seems likely that sharper increases will be seen in older populations. For example, it is estimated that dementia in those aged 90+ will increase from 1,108 to 1,697, a 53.2% increase, whereas dementia in those aged 65-69 will increase from 318 to 363, a 14.2% increase.

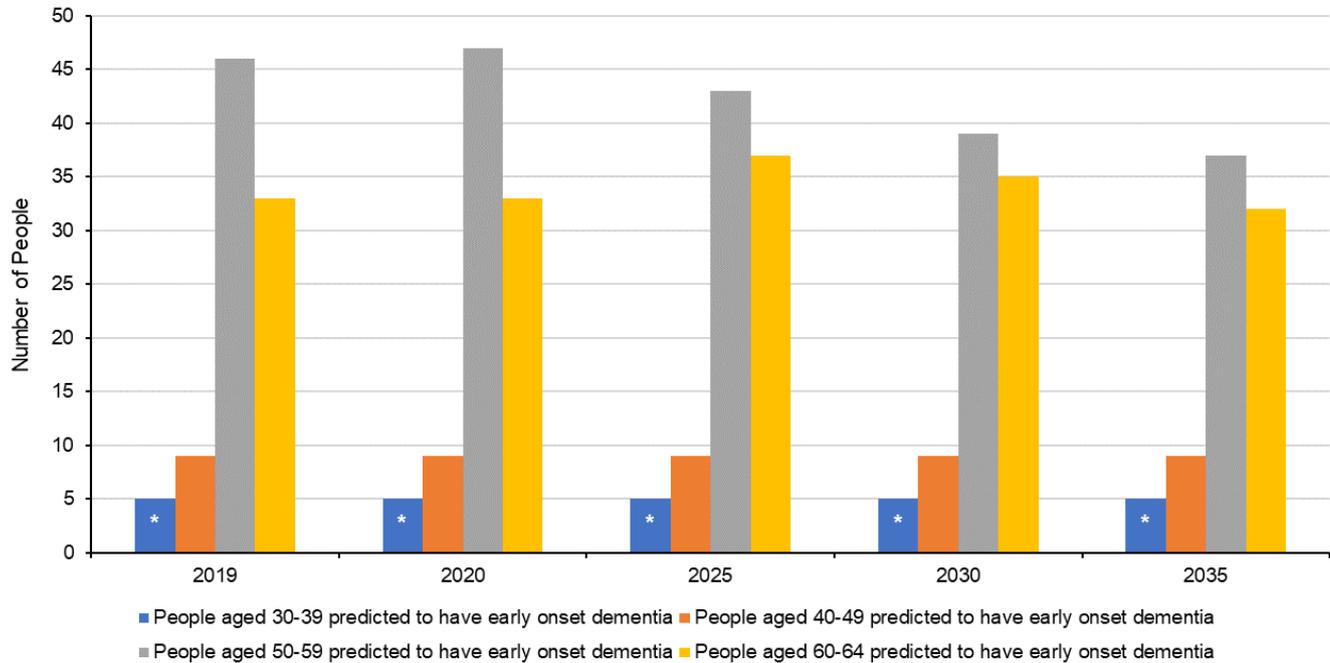
**Figure 3:** Estimated projections of people with late onset dementia, by age group, Wirral, 2019-2035



Source: [POPPI](#)

Unlike late onset dementia, the number of people projected to be affected by early onset dementia is estimated to decrease in Wirral (Figure 4). Projections from PANSI ([Projecting Adult Needs and Service Information](#)) show that, in Wirral in 2019, 93 people were affected by early onset dementia. This is estimated to decrease to 83 people by 2035; a decrease of 12%.

**Figure 4:** Estimated projections of people with early onset dementia, by age group, Wirral, 2019-2035



Source: [PANSI](#)

Note: (\*) Indicates a true value of less than 5 people which have been asterisked to protect against identification

Table 1 below shows that the estimated total number of people (i.e. the total of early and late onset dementia) projected to have dementia in Wirral will increase from 5,086 in 2019 to 7,155 in 2035; an increase of approximately 40.7% in 16 years. This is lower than the estimated increase in England between the same period of 50.2%.

**Table 1:** Estimated projections of people of all ages with dementia, Wirral and England, 2019-2035

Year	2019	2020	2025	2030	2035	% change between 2019 and 2035
Total number of people estimated to have dementia (Wirral)	5,086	5,138	5,656	6,401	7,155	40.7%
Total number of people estimated to have dementia (England)	743,154	758,230	855,191	980,558	1,116,484	50.2%

Source: [POPPI](#) and [PANSI](#)

## Gender

Estimates for dementia are also broken down by gender. For early onset dementia in Wirral, prevalence figures are split 58.2% males and 41.8% females. On the other hand, for late onset dementia in Wirral, it is estimated to be more prevalent in females than males – split 64.3% to 35.7%. This follows a similar pattern to national prevalence estimates – early onset dementia being split 58.8% male to 41.2% female whereas late onset dementia is split 63.4% female and 36.6% male.

**Figure 5:** Estimated early onset dementia breakdown by gender, by Wirral (left) and England (right), 2019



Source: [PANSI](#)

**Figure 6:** Estimated late onset dementia breakdown by gender, by Wirral (left) and England (right), 2019



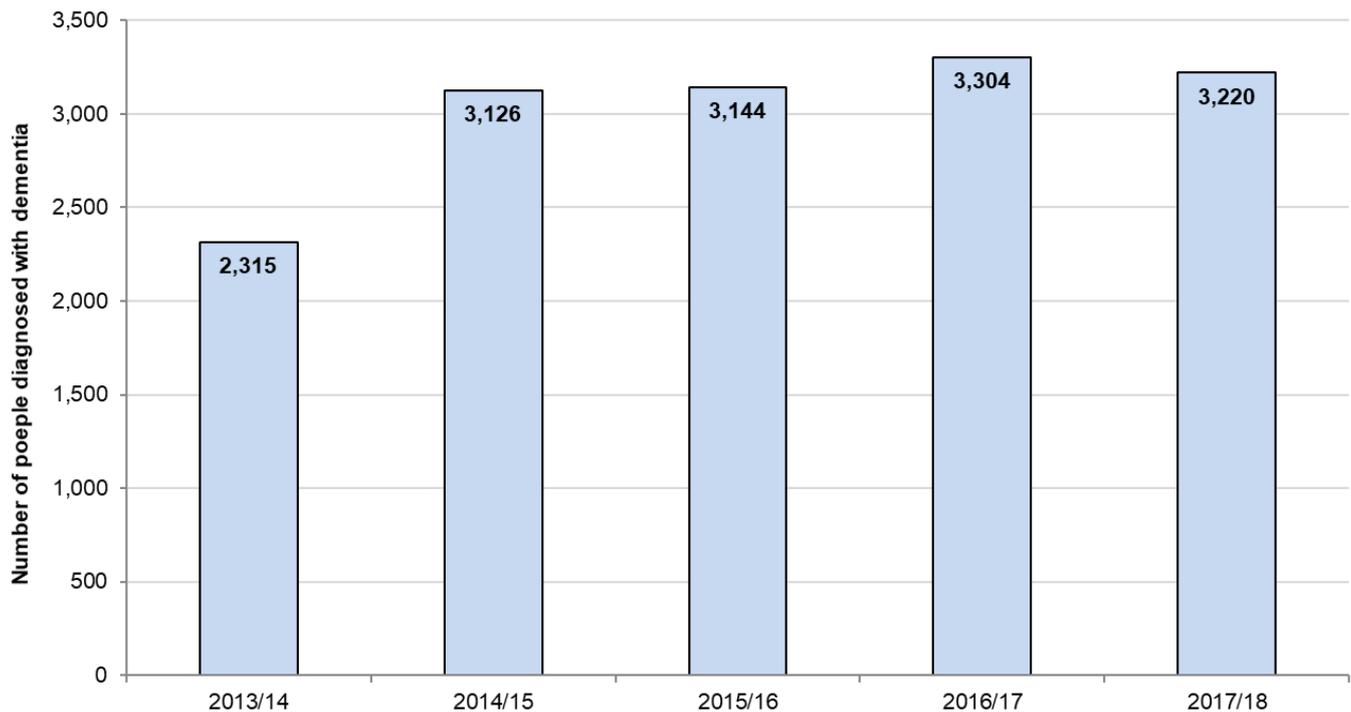
Source: [POPPI](#)

## Wirral Clinical Commissioning Group (CCG)

Figure 7 below shows the most recent Quality and Outcomes Framework ([QOF](#)) figures of recorded dementia diagnosis from GP practice registers. The figure shows that there are currently 3,220 adults in Wirral who are registered with a GP with a recorded diagnosis of dementia. This equates to around 1.2% of the GP-registered adult population of Wirral.

The QOF also recorded that in January 2019, the number of Wirral residents, aged 65 and over with dementia, was recorded as 3,073 (or 4.4% of the 65+ population). As the previous paragraph explains, there are a total of 3,220 adults (of any age) with dementia. This therefore suggests that approximately 150 people under the age of 65 have a diagnosis of dementia – classified as early onset dementia.

**Figure 7:** Trend in Quality Outcomes Framework (QOF) recorded dementia diagnoses, by all ages, Wirral Clinical Commissioning Group (CCG), 2013/14 to 2017/18



Source: [Public Health Outcomes Framework](#)

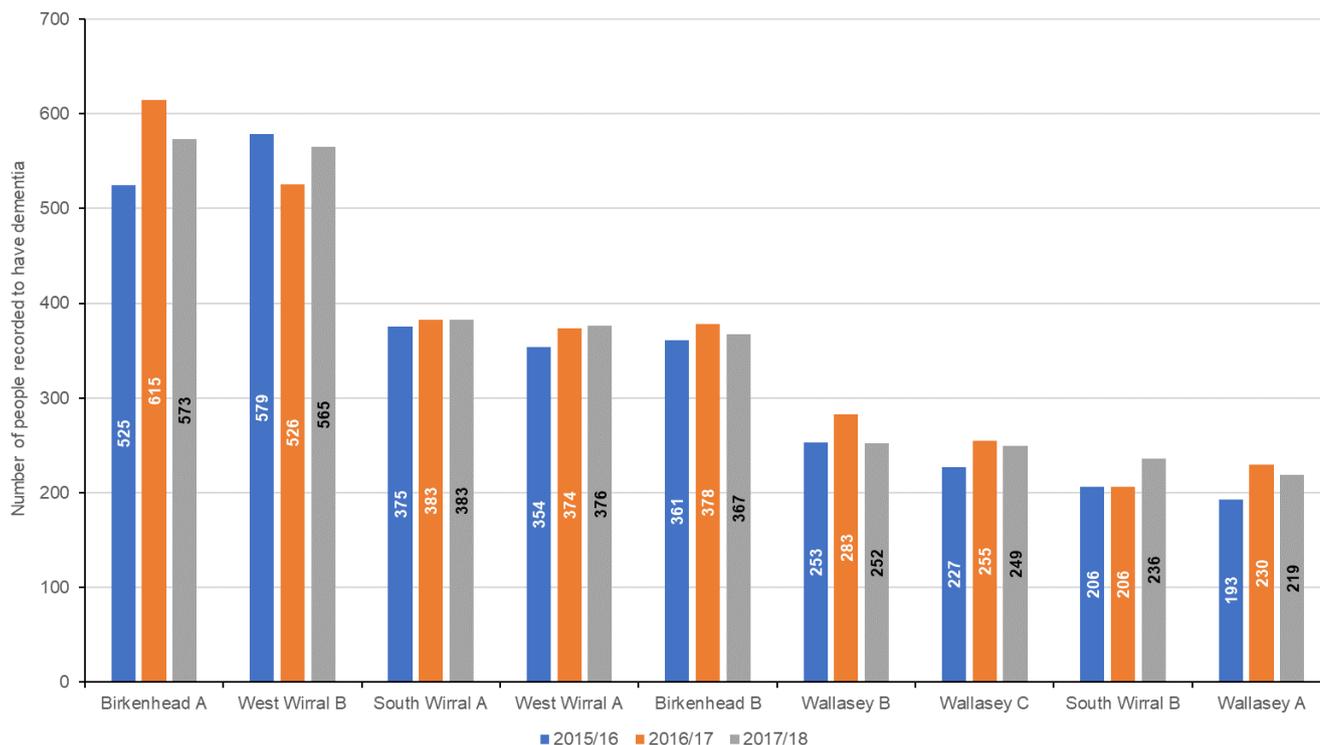
### Wirral Neighbourhoods

The Commissioning and Transformation Strategy developed by Wirral Health & Care Commissioning sets an ambition of providing services that are clinically and financially sustainable through greater integration of care, reduction in duplication and flexibility in approach of delivery to meet local population needs.

The key transformation has been the establishment of 9 Integrated Neighbourhood Teams across the peninsula based on geographical area as opposed to organisation. These teams include an integrated workforce, spanning primary, secondary, mental health, social care and third sector organisations. Neighbourhood teams and patient care will be wrapped around the person and the neighbourhood where they live to provide proactive joined up care. For more information on Neighbourhoods, please see Map 1a of the Appendix.

Figure 8 shows that the Birkenhead A and West Wirral B neighbourhoods have the highest recorded dementia diagnoses of the neighbourhoods in Wirral. These two neighbourhoods make up over a third of all people with a recorded dementia diagnosis. On the other hand, those in the South Wirral B and Wallasey A neighbourhoods have the fewest people recorded as having dementia.

**Figure 8:** Trend in Quality Outcomes Framework (QOF) recorded dementia diagnosis by Wirral Neighbourhoods, 2015/16 – 2017/18



**Source:** Quality Outcomes Framework ([QOF](#))

**Notes:** The Neighbourhoods of Wirral are a newly introduced set of geographies to help support commissioners. See Appendix Map 1a for more information

There is a high concentration of care homes in the Birkenhead A neighbourhood. This perhaps explains why the number of people recorded as having dementia is high in that neighbourhood, despite having a low 65+ population overall. This is evident in Map 2a of the Appendix. West Wirral B, on the other hand, has a much larger 65+ population. This may explain the high numbers of people diagnosed with dementia within that neighbourhood.

### Hospital Admissions

Figure 9 below provides an indication of the use of inpatient hospital services for people diagnosed with dementia. Inpatient care requires patients to be admitted to hospital so that their conditions can be closely monitored during a procedure and during the resulting recovery period. This could be anything from a planned procedure such as an operation, to the monitoring of conditions after an accident or a fall. Wirral, Cheshire and Merseyside and England have all seen the ratio of inpatient service use of people with a recorded dementia diagnosis gradually increase – most notably 64.9 per 100 in Wirral in 2015/16 to 73.2 per 100 in 2017/18 (an increase of 8.3%).

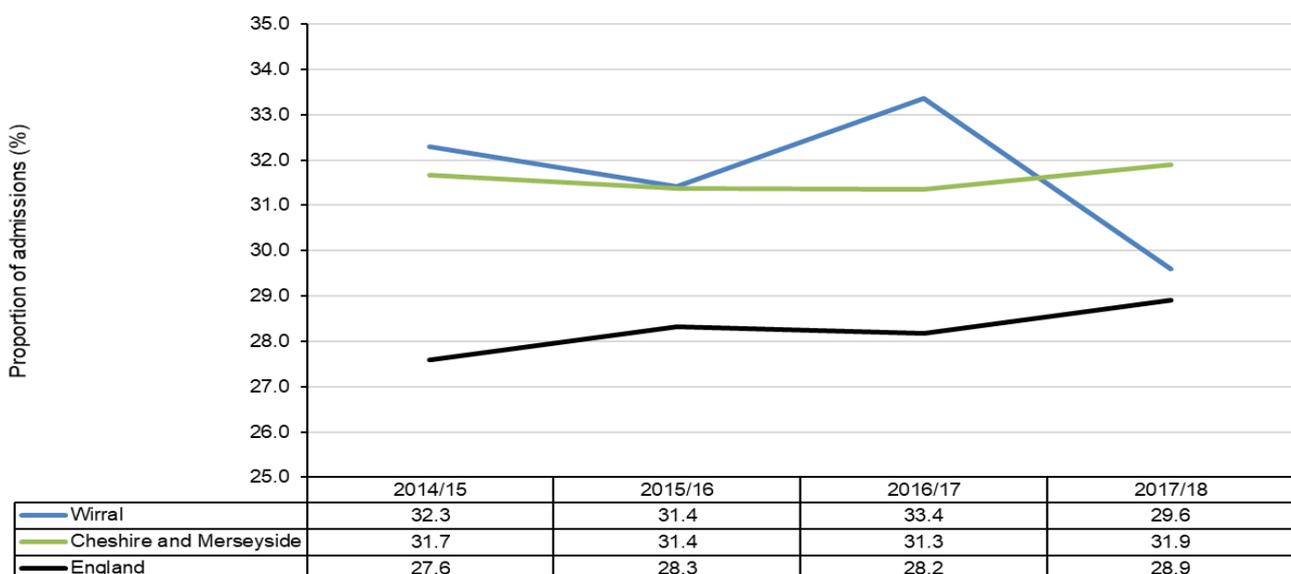
**Figure 9:** People with dementia using inpatient hospital services as a percentage of recorded diagnosis of dementia (all ages), Wirral, Cheshire and Merseyside and England, 2015/16 to 2017/18



Source: [Public Health Outcomes Framework](#)

Figure 10 shows the proportion of emergency short stay dementia-related admissions in those aged 65+. Between 2014/15 to 2016/17 the proportion of dementia-related short stay emergency admissions had been gradually increasing in Wirral. The most recent figures have shown, however, a significant decrease (from 33.4% to 29.6%) – unlike Cheshire and Merseyside and England which have both shown increases (from 31.3% to 31.9% and from 28.2% to 28.9% respectively). Almost one in three dementia-related emergency admissions was for one night or less. This suggests that these patients did not perhaps need to be in an acute setting and could have instead been managed in the community. Two thirds of all dementia-related emergency admissions were therefore longer than 24 hours.

**Figure 10:** Proportion of dementia-related short stay emergency admissions (aged 65+), Wirral, Cheshire and Merseyside and England, 2014/15 to 2017/18

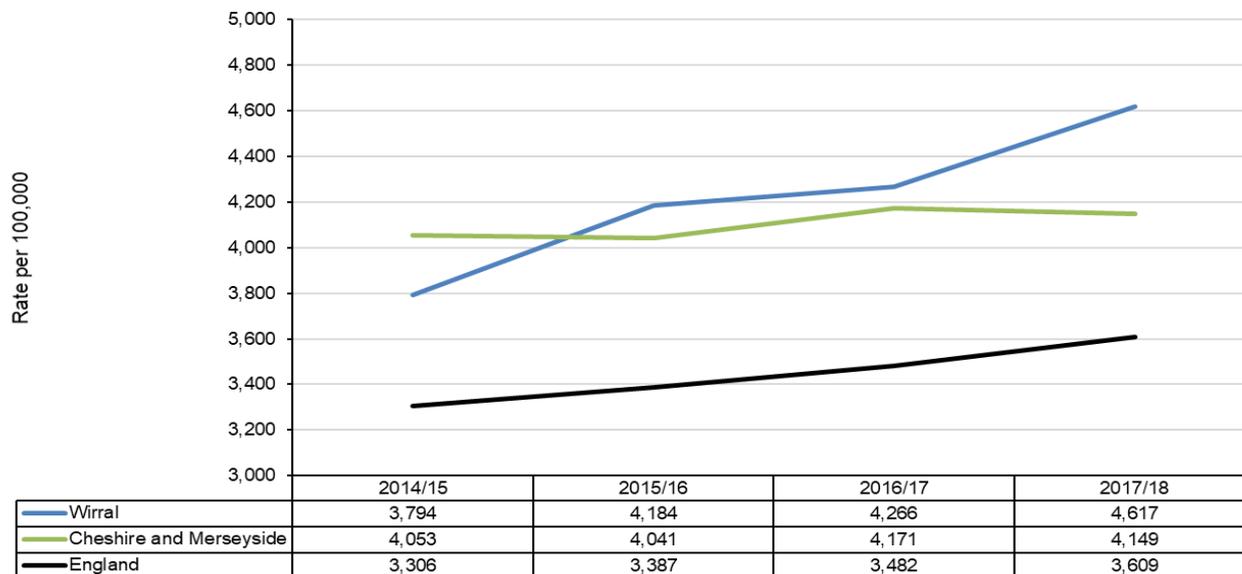


Source: [Public Health Outcomes Framework](#)

Note: Short stays are classed as 1 night or less with dementia being mentioned in any diagnosis field

Figure 11 below shows that the rate of dementia-related emergency admissions for people aged 65+ has steadily increased year-on-year in Wirral. Wirral has also had consistently higher rates of dementia related emergency admissions than that of Cheshire and Merseyside and England. Most recent figures continue to follow this trend with Wirral rates (4,617) again being higher than Cheshire and Merseyside (4,149) and England (3,609).

**Figure 11:** Directly standardised rate of dementia-related emergency admissions (aged 65+), Wirral, 2012/13 to 2017/18

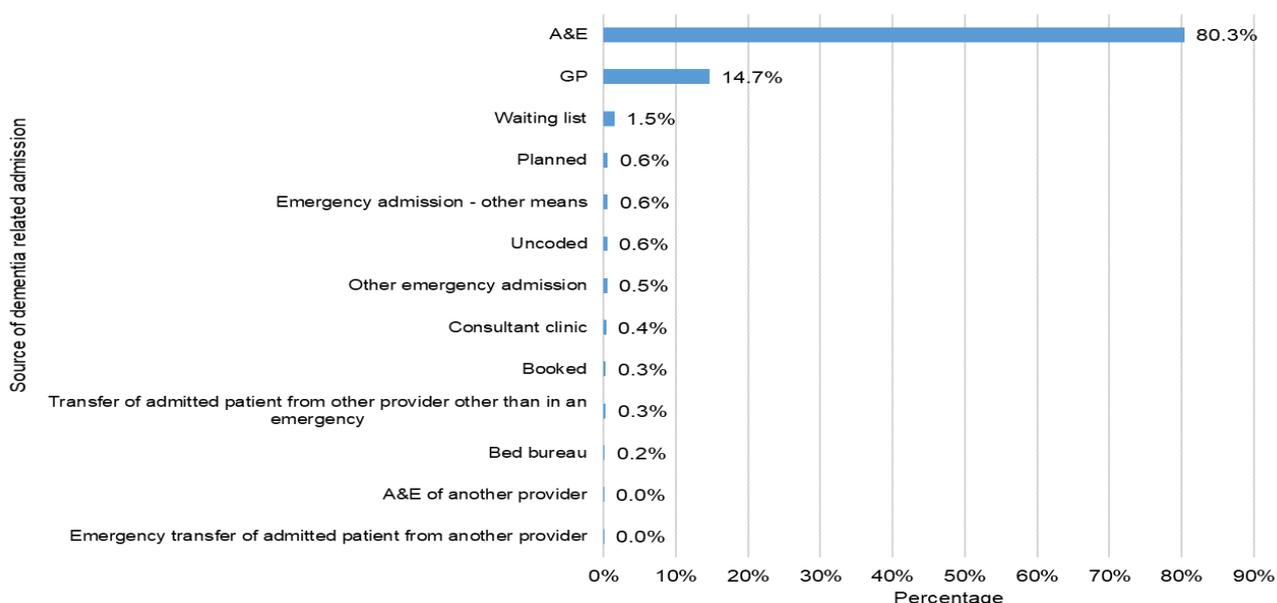


Source: [Public Health Outcomes Framework](#)

Note: A directly standardised rate (DSR) is an age-standardised rate that is used to allow comparison between populations which may contain different proportions of people of different ages

Figure 12 shows the sources of dementia-related admissions to acute hospital. 80.3% of all admissions between 2013/14 and 2017/18 with a dementia-related primary or secondary diagnosis were admitted via an Accident and Emergency Department. Almost all the other admissions came via emergency referrals to hospital by a GP. This means most dementia admissions were unplanned. Only 2% of dementia-related admissions to hospital were elective.

**Figure 12:** Acute hospital sources of dementia-related inpatient admissions, Wirral, 2013/14 to 2017/18 (5 financial years pooled)



Source: Secondary Users Service (SUS) data, Wirral CCG, 2019

Patients with dementia present at hospital with a broad range of diagnoses in conjunction with any dementia-associated issues. Over a five-year period from 2013/14 to 2017/18 there were over 560 different primary diagnoses for Wirral inpatients with a dementia-related condition also reported. The most common of these primary conditions were “pneumonia” (7.7% of all cases) followed by “disorders of the urinary system” (6.6% of all cases) and then “septicaemia” (4.4% of all cases).

These primary conditions were defined by the first three out of four characters in their ICD-10 codes and so do not represent all the diagnoses possible – for instance the pneumonia category listed here does not include other forms of bacterial or viral pneumonia.

This highlights that people with dementia are very likely to present at hospital with conditions other than dementia directly and that many of these co-morbidities can increase the risk and duration of hospital admissions. The tables below compare the percentage of hospital inpatient admissions by age group and length of stay (LoS) for admissions involving a dementia diagnosis (Table 2) against admissions involving any diagnosis (Table 3).

Zero-day length of stay activity (where a patient is discharged within 24 hours of admission) makes up 61% of all activity when looking across all ages and diagnoses. 91% of all admissions for any diagnosis were discharged within a week of admission. In contrast, only 59% of dementia-associated activity involved hospital stays of less than a week, and only 17% of dementia-associated activity was discharged within 24 hours. Over one third (35%) of dementia-associated activity was discharged between 1-5 weeks. This shows that patients with dementia diagnoses tend to stay in hospital longer than even their comparably aged peer group. Older adults (aged 60+) made up 97% of all dementia-associated activity.

**Table 2:** Percentage of inpatient admissions with dementia diagnosis split by age band and spell length of stay, 2013/14 - 2017/18

Age Group	LoS Banding					Total admitted by age group
	0 days	< 1 week	1-5 weeks	5-12 weeks	> 12 weeks	
<b>60 and under</b>	<b>0.6%</b>	<b>1.4%</b>	<b>0.8%</b>	<b>0.2%</b>	<b>0.1%</b>	<b>3.0%</b>
61 - 65	0.4%	0.7%	0.4%	0.1%	0.1%	1.7%
66 - 70	0.9%	1.7%	1.2%	0.3%	0.1%	4.3%
71 - 75	1.9%	3.2%	2.5%	0.4%	0.2%	8.2%
76 - 80	2.7%	6.7%	5.1%	1.0%	0.2%	15.7%
81 - 85	4.2%	10.3%	8.4%	1.3%	0.2%	24.4%
Over 85s	6.3%	17.6%	16.2%	2.4%	0.2%	42.7%
<b>Over 60s</b>	<b>16.5%</b>	<b>40.1%</b>	<b>33.8%</b>	<b>5.6%</b>	<b>1.0%</b>	<b>97.0%</b>
<b>All ages</b>	<b>17.1%</b>	<b>41.5%</b>	<b>34.6%</b>	<b>5.8%</b>	<b>1.0%</b>	<b>100.0%</b>

Source: Secondary User Service (SUS) data, Wirral CCG, 2019

Note: LoS is an acronym for 'Length of Stay'

**Table 3:** Percentage of inpatient admissions with any diagnosis split by age band and spell length of stay, 2013/14 - 2017/18

Age Group	LoS Banding					Total admitted by age group
	0 days	< 1 week	1-5 weeks	5-12 weeks	> 12 weeks	
<b>60 and under</b>	<b>33.5%</b>	<b>18.3%</b>	<b>2.2%</b>	<b>0.2%</b>	<b>0.1%</b>	<b>54.4%</b>
61 - 65	4.9%	1.7%	0.5%	0.1%	<b>0.0%</b>	7.2%
66 - 70	6.0%	2.0%	0.7%	0.1%	<b>0.0%</b>	8.9%
71 - 75	5.4%	2.0%	0.8%	0.1%	<b>0.0%</b>	8.3%
76 - 80	5.0%	2.0%	1.0%	0.1%	<b>0.0%</b>	8.1%
81 - 85	3.7%	1.8%	1.1%	0.1%	<b>0.0%</b>	6.8%
Over 85s	2.4%	2.1%	1.6%	0.2%	<b>0.0%</b>	6.3%
<b>Over 60s</b>	<b>27.3%</b>	<b>11.7%</b>	<b>5.7%</b>	<b>0.7%</b>	<b>0.1%</b>	<b>45.6%</b>
<b>All ages</b>	<b>60.8%</b>	<b>30.0%</b>	<b>7.9%</b>	<b>1.0%</b>	<b>0.2%</b>	<b>100.0%</b>

Source: Secondary User Service (SUS) data, Wirral CCG, 2019

Note: LoS is an acronym for 'Length of Stay'

### Alcohol related brain damage (ARBD)

Alcohol related brain damage (ARBD) includes a number of specific conditions, the most common being alcohol-related dementia, however, none of these conditions come within the dementia umbrella. Unlike more common causes of dementia, people with ARBD can make a full or partial recovery dependent upon following good care and abstaining from alcohol.

Table 4 compares the number of dementia-related and ARBD-related admissions (primary or secondary diagnosis) to hospitals between 2013/14 and 2017/18 from patient's resident in Wirral. The number of dementia-related admissions increases each consecutive year, from 2,436 in 2013/14 to 4,241 in 2017/18. The ARBD figures use a smaller set of diagnosis codes with only limited overlap with the dementia diagnosis codes but these figures also increase over time. This could be due to increased diagnosis of dementia or more complete reporting of secondary diagnoses.

**Table 4:** Number of ARBD-related and dementia-related admissions, Wirral, 2013/14 to 2017/18

Financial Year	2013/14	2014/15	2015/16	2016/17	2017/18
Dementia-related admissions	2,436	3,016	3,327	3,574	4,241
ARBD-related admissions	84	83	94	118	138

Source: Secondary Users Service (SUS) data, Wirral CCG, 2019

Note: This table includes admissions with zero-day length of stay

### Treatment

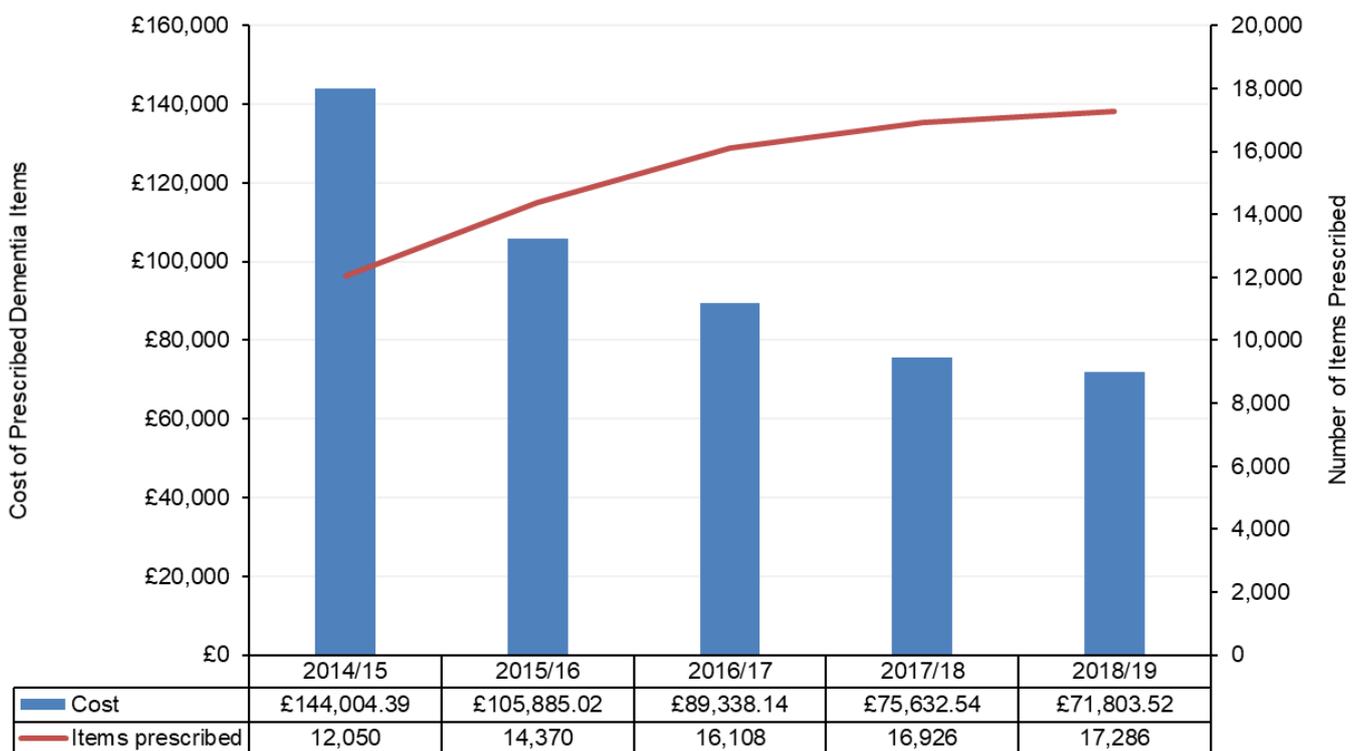
There is currently no known cure for dementia, however there are several ways in which the symptoms can be alleviated; drug treatment and non-drug treatment, such as talking therapies, cognitive stimulation therapy and other alternative therapies. People living with mild to moderate Alzheimer's disease may be prescribed one of the following three medications which are a group of medicines called acetylcholinesterase inhibitors; [Donepezil](#), [Rivastigmine](#) or [Galantamine](#). For people with moderate Alzheimer's disease who cannot take any of the above medications, or suffer from more severe symptoms of Alzheimer's disease, another medication available is [Memantine](#). People, with an established diagnosis of moderate or severe Alzheimer's disease, who are already taking one of the acetylcholinesterase inhibitors may also be prescribed memantine.

People with dementia who are either at risk of harming themselves or others, or who are experiencing agitation, hallucinations or delusions that are causing them severe distress may be prescribed an antipsychotic medicine, for example, [Olanzapine](#), [Risperidone](#), [Quetiapine](#), [Amisulpride](#), [Sulpride](#) or [Haloperidol](#).

As Figure 13 shows, prescribing costs for dementia medications have decreased over the last 5 financial years; 50.1% between 2014/15 and 2018/19. This is despite the number of dementia items (donepezil hydrochloride, galantamine, memantine hydrochloride and rivastigmine) prescribed to individuals increasing. There are several reasons to explain this trend, such as:

- The cost of donepezil hydrochloride has decreased over the five years. In 2014/15 two different forms of donepezil hydrochloride orodispersible tablets were prescribed – sugar and non-sugar free. Non-sugar free donepezil hydrochloride was significantly more expensive and is no longer prescribed, instead the more cost-effective sugar free donepezil hydrochloride is prescribed only
- The number of memantine hydrochloride items prescribed has doubled across five years. In June 2018 NICE published the Dementia guidelines which recommend dual therapy with memantine for certain patients. The cost has decreased by approximately £25,000.
- Rivastigmine and galantamine have also decreased in both numbers prescribed and cost.

**Figure 13:** Cost of prescribing dementia medications, Wirral, 2014/15 to 2017/18



Source: NHS Digital and Wirral Clinical Commissioning Group (CCG), 2019

For people living with mild to moderate dementia who also have mild to moderate depression or anxiety, psychological treatments are the intervention recommended by NICE guidance. The drug [Trazodone](#) is used a treatment for behavioural and psychological manifestations of dementia, although NICE guidance recommends that antidepressants should not be routinely prescribed unless they are indicated for a pre-existing severe mental health problem.

Community support services play an important role in helping people to manage and live well with dementia. Some of the services offered in Wirral include support groups, carer services and reading groups. More details of these services can be found in the [Current Activity and Services](#) section.

## **Dementia and Social Care**

One of the priorities of Wirral Health and Care Commissioning (WHaCC) is to support people with dementia to remain living independently in their own home for as long as they can. A range of social care services are commissioned to deliver person centred care and support to individuals with dementia and their carers.

Non-residential care, or domiciliary care, provides care and support for people with dementia in their own home which is tailored to the individual and their needs. This care may include support with household tasks, personal care or other activities that support the individual to maintain their independence and quality of life.

A mobile night's service has been introduced on Wirral which provides planned and unplanned support throughout the night. This service aims to work seamlessly and collaboratively with other health and social care services to support people in their own homes, while also preventing admissions to acute care settings and reducing lengths of stay in hospital wherever possible.

There is an awareness that there are people with dementia who want to remain as independent as possible; however, due to the potential risks of living alone as the condition progresses, they may require additional intensive support in order to maintain their safety.

This has led to the development of extra care accommodation, with support staff on site providing 24-hour care along with a range of communal services such as hairdressers, shops, garden areas and social activities. Such a variety of services help to enable people with dementia to remain as independent as they can within a safe and secure environment. There is also residential care provision for people who are approaching the later stages of dementia, whereby an individual is cared for in a care or nursing home, however this option is only considered when other options have been exhausted.

For older people, including those with dementia, there are a range of day care models available in Wirral for people who meet the eligibility criteria under the Care Act 2014. This includes commissioned services with the third sector or accessing alternatives with a direct payment. Some day care services are available 7 days a week in order to ensure that people have a choice about when they would like to attend and to be flexible around carers needs. There is also a specialist day care service for people with early onset dementia which is provided by Age UK Wirral and operates 3 days per week. Day care centres provide an opportunity for people with dementia to socialise with others and enjoy activities aimed at motivating and stimulating people with dementia to help maintain functional skills. They also provide much needed respite for carers of people with dementia to enable them to keep caring for their loved one for longer.

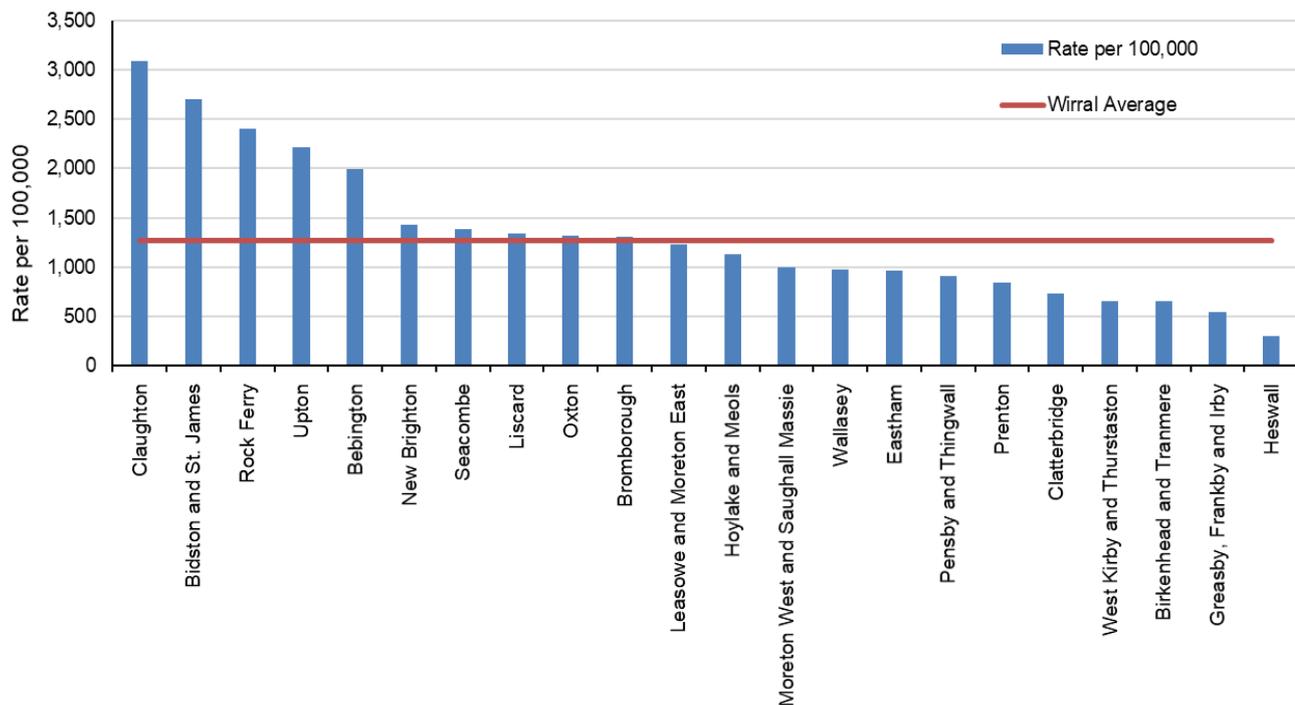
With all areas of social care, there is a drive to develop assistive technology options which will support people with dementia to remain living independently within their own homes, and which will also provide their carers piece of mind as they are able to monitor their loved one and know that they are safe. WHaCC are identifying and piloting new technology which will support people with dementia in a range of situations.

Additionally, carers on Wirral can download and use [Jointly](#) for free. *Jointly* is an app created by Carers UK that helps Carers to organise care for their loved one – setting up visits, passing information to each other and keeping records of medication and key professionals such as Dementia Nurses, GP and social care workers. Wirral Council also offers free access to a range of e-learning resources to help Carers understand and find out about their rights, where to find support and what they can expect from health and social care organisations.

For advice and guidance on how to access adult social care support please visit the Wirral Council website [here](#) or alternatively contact the Central Advice and Duty Team (CADT) which is a part of Adult Social Services by ringing 0151 514 222 or email [cadt@nhs.net](mailto:cadt@nhs.net)

Figure 14 shows the rate per 100,000 of people aged 65+ with dementia who are actively using Wirral Council services by ward. The largest proportion of services users are located in Claughton - over 3,000 people per 100,000. The lowest rates are in Birkenhead and Tranmere, Greasby, Frankby and Irby and Heswall.

**Figure 14:** Rate per 100,000 of active service users aged 65+ with dementia by ward, Wirral, January 2019



**Source:** Department for Adult Social Services

**Note:** The rate has been calculated using the mid-2017 ward population estimates produced by ONS as mid-2018 figures are not yet available at this granularity

Within all areas of social care, there is a drive to develop assistive technology options which can support people with dementia to remain living independently within their own homes, and also provide carers peace of mind. Examples of technology already used by people with dementia or other cognitive difficulties include:

- Hot water dispensers to replace kettles to reduce the risk of scalding
- Talking clocks and devices that provide reminders to take medication, have a drink or eat a meal
- Home monitoring systems that build up a picture of somebody's movements and patterns of behaviour
- GPS tracking devices. This is a particularly sensitive area of work and all those involved must understand the features and consequences of using this technology.
- Battery-powered LED lighting strips that turn on at night responding to movement can reduce the risk of falls
- Medication dispensing devices

WHaCC is currently in the process of identifying and piloting new assistive technologies which will support people with dementia in a range of situations.

The table below shows the top 3 provisions that are commissioned through the department for adult social services (DASS). The service with the highest proportion of active users is assistive technology. This will be a range of equipment that can be accessed to help to support people maintain their independence, such as those listed above.

Home care, the second highest service use, helps to support people in their own homes and is provided to 16.8% of active DASS service users, whilst long term residential care supports 14.5%. Both assistive technology and home care help to support the aim of the WHaCC to maintain people in their own homes for as long as they can remain independent and delay the need for residential care.

**Table 5:** Top 3 social care provisions for individuals actively receiving support and recorded as having dementia, Wirral, January 2019

Service Provision	Percentage using service provision
Assistive Technology	18.9%
Home Care – Personal Care	16.8%
Residential – EMI – Long Term	14.5%

**Source:** Department for Adult Social Services, Wirral Council

Table 6 shows the percentage of people with dementia who are currently residing in residential care. Of all the active DASS service users aged 65+ with dementia, 24.5% (1 in 4) are provided with some form of residential care. This figure is then further broken down to show the types of residential care individuals are provided. For example, 14.5% are living in long term elderly mental infirm units whereas only 0.7% are provided with short term residential care.

**Table 6:** Residential care provision for individuals actively receiving support and recorded as having dementia, Wirral, January 2019

Residential Care Provision	Percentage using service provision
Residential Care (all)	24.5%
Long term (Elderly Mental Infirm unit)	14.5%
Short term (Elderly Mental Infirm unit)	1.2%
Long Term	8.2%
Short Term	0.7%

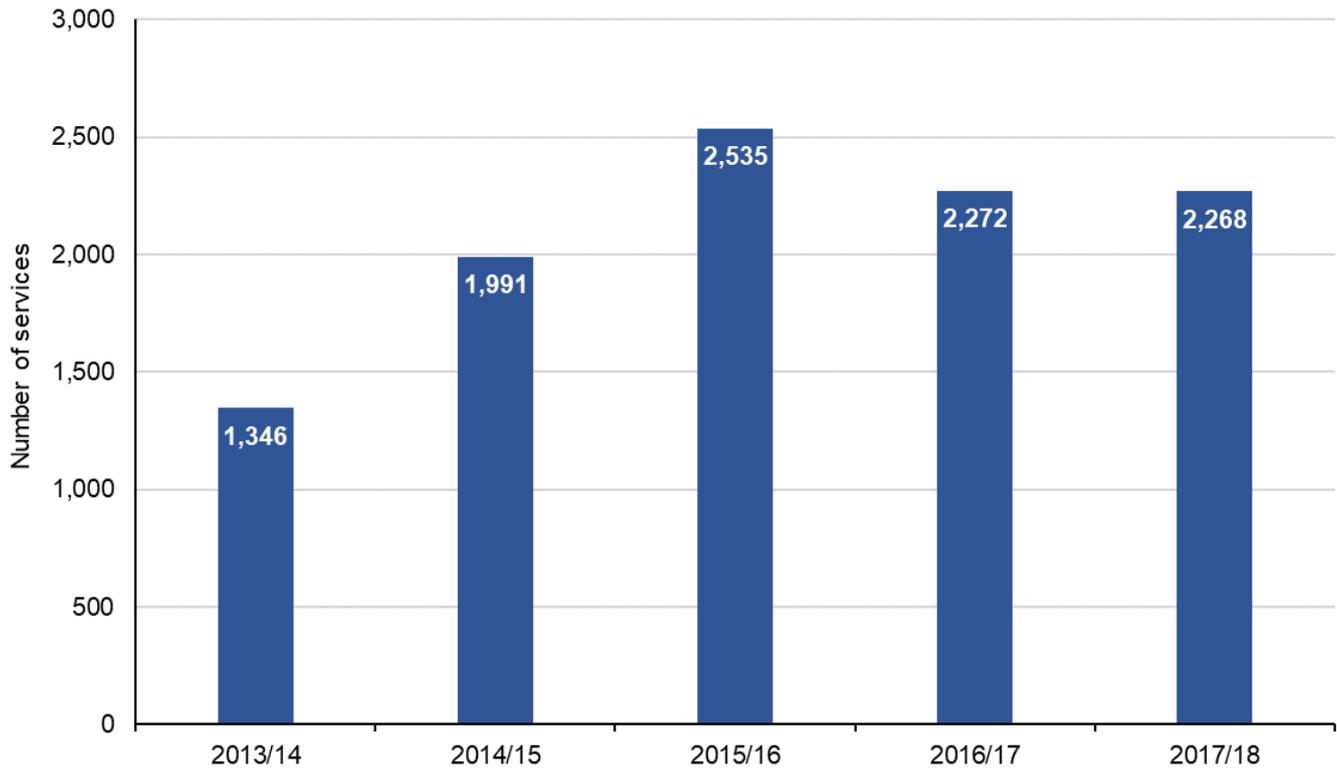
**Source:** Department for Adult Social Services, Wirral Council

As of 2017/18, there are around 1,238 people in Wirral were receiving social care services with a record of having dementia. Of these, 94% are aged 65 and over, with 6% aged between 49-64 years.

Figure 15, below, shows the total number of services provided to all people (regardless of age) recorded as having dementia from adult social care. Between 2013/14 and 2017/18 there has been an increase of just over 900 services (68%) provided to individuals with dementia.

However, since 2015/16 there has been a slight decrease in the number of services provided, with 2,268 services provided to individuals in 2017/18 – almost 300 fewer than in 2015/16.

**Figure 15:** Number of services provided by Wirral Department of Adult Social Services (DASS) to individuals recorded as having dementia, Wirral, 2012/13 to 2017/18



**Source:** Department for Adult Social Services, Wirral Council

**Note:** Individuals may be double counted as they may have been provided with multiple service throughout the year. For example, one individual may have been provided with long-term residential care, then provided with assistive technology and then provided with short-term residential care all in a given year.

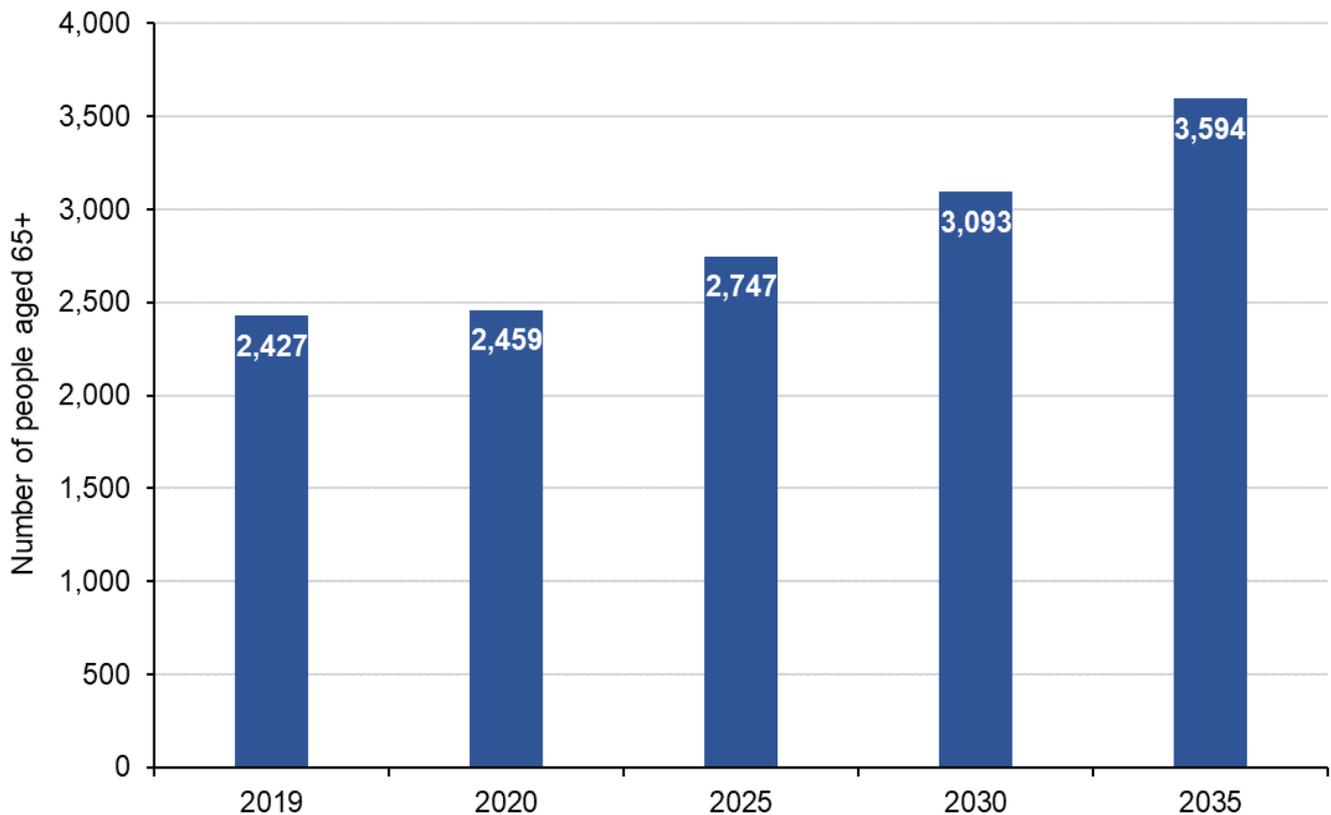
## **Older people’s living arrangements**

### **Older people living in care homes**

[The Alzheimer’s Society](#) suggests that living with dementia in a care home can mean more than just a loss of memory. It can mean losing connections with neighbours and friends, or to hobbies, sports and pastimes. It can lead to changes in health and wellbeing and to depression as the individual adjusts to a very different way of life.

Figure 16 below shows that the number of older people (aged 65+) living in care homes is estimated to increase from approximately 2,427 people to 3,594 people by 2035; an increase of 1,167 people (or 48%) from 2019.

**Figure 16:** Projected number of older people (65+) living in care homes, Wirral, 2019 to 2035



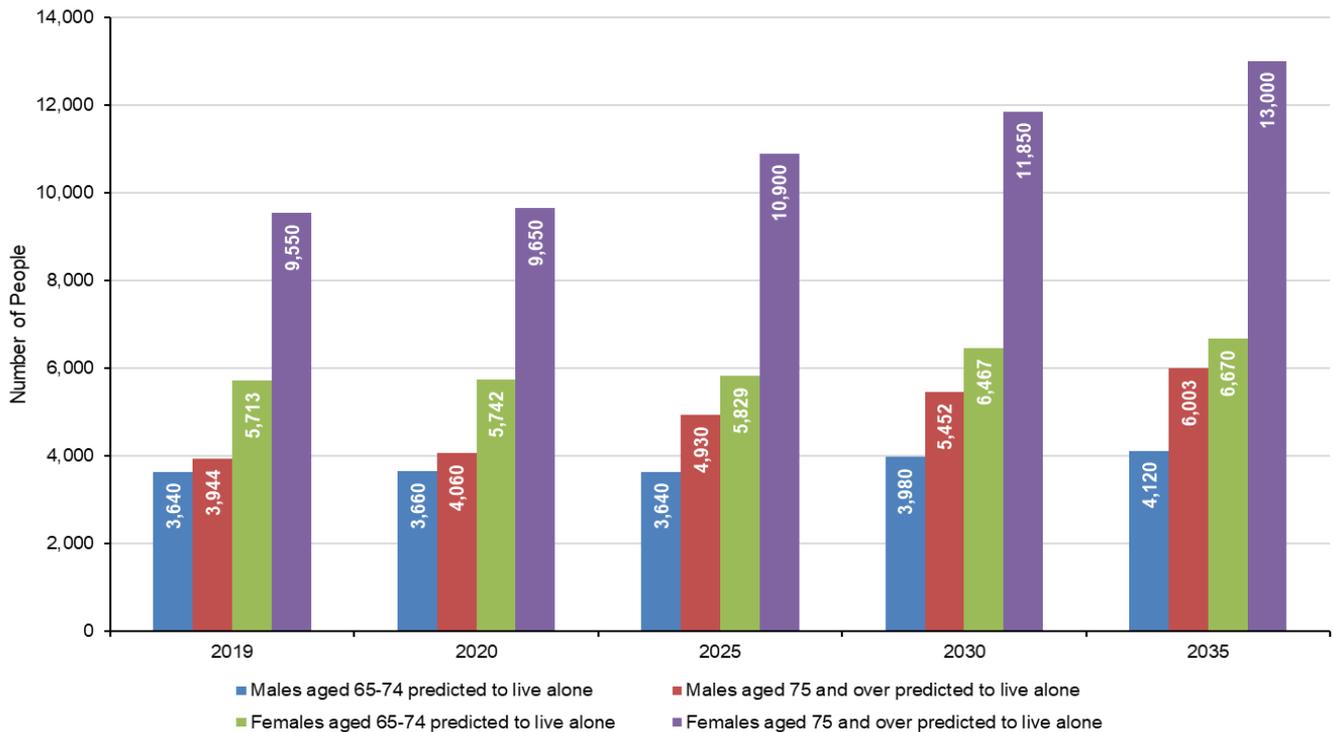
Source: [POPPI](#)

### Older people living alone

People who have dementia and live alone are at greater risk of social isolation and loneliness. Research, conducted by [the Alzheimer's Society](#), has found that 62% of people with dementia who live alone feel lonely compared to 38% of all people with dementia.

Figure 17 shows that the number of people aged 65 and over living alone will increase over the next 15 years. The chart also highlights the largest group of older people living alone will be females aged 75 and over – the number of which is expected to increase from 9,550 in 2019 to 13,000 in 2035.

**Figure 17:** Projected numbers of people aged 65 and over living alone, by age and gender, 2019 to 2035, Wirral



Source: [POPPI](#)

## Mortality

Table 7 below shows the breakdown of dementia-related deaths (aged 65+) that occurred in three different environments – at home, at a care home and in hospital. Between 2011/12 and 2017/18 the proportion of dementia-related deaths at home has increased both in Wirral (5.1% to 7.9%) and England (6.4% to 9.9%). Dementia-related deaths that occurred in hospital has decreased substantially, however, from 33.4% in Wirral to 31.7% and from 35.9% in England to 30.5%. Over half of all dementia-related deaths in Wirral and in England occur in a care home. This trend has stayed relatively consistent across the 7 years of data shown.

**Table 7:** Breakdown of dementia-related deaths (aged 65+) that occurred at home, care home or at hospital, Wirral and England, 2011/12 to 2017/18

Year	Wirral			England		
	Home	Care Home	Hospital	Home	Care Home	Hospital
2011/12	5.1%	58.8%	33.4%	6.4%	56.3%	35.9%
2012/13	5.5%	57.9%	34.5%	7.1%	58.1%	33.4%
2013/14	5.2%	58.5%	34.9%	7.4%	58.6%	32.6%
2014/15	7.9%	61.5%	29.5%	8.4%	58.5%	31.4%
2015/16	6.5%	59.7%	30.5%	8.9%	59.2%	30.4%
2016/17	10.4%	54.7%	32.2%	9.7%	57.6%	30.9%
2017/18	7.9%	58.2%	31.7%	9.9%	58.0%	30.5%

Source: [Dementia Profile, Public Health England](#)

**Note:** These figures do not sum to 100%. This is because there may be other areas, such as hospices or religious establishments, that aren't recorded here, in which older people with dementia may have died.

## What are the views of local people, communities and stakeholders?

### Wirral Dementia Community Engagement

In December 2018, Wirral Health and Care Commissioning (WHaCC) undertook an engagement exercise with a range of stakeholders including; people living with dementia, carers/family and friends of people with dementia and various staff across the health, social, voluntary and charity sectors who work with people living with dementia.

The purpose of the engagement was to understand people's experience of living with dementia including the assessment/diagnosis process, ability to self-care, the type of support received from statutory and non-statutory organisations and wider community support. The engagement exercise highlighted what is working well with Wirral's dementia offer, what requires improving, and where the gaps are. Key findings from this engagement are summarised below:

- Education of preventative health messages (such as importance of regular exercise, balanced diet, smoking cessation etc.) is vital
- More education regarding what it's like to live with dementia, including common behaviours, symptoms and how to access help for a diagnosis
- Improve the waiting times between a referral from a GP and assessment/diagnosis in secondary care
- Post diagnostic support – people need to access the right care and support following a diagnosis within the community. This support should be person centred and holistic
- Involving people with dementia and carers in their care planning with health professionals
- Training for statutory and voluntary sector staff in dementia awareness to support them to provide tailored and quality care to individuals
- Maintain the status of "Working to become a dementia friendly community"
- Good quality provision and availability of respite care including day care centres, domiciliary care and short-term respite
- Information regarding advance care planning should be shared with people with dementia and carers with end of life wishes recorded in care records

The next steps for WH&CC are to include these insights in the refresh of the Wirral Dementia Strategy, along with key outcomes that Healthy Wirral want to achieve over the next 4 years.

The summary report on the engagement exercise can be accessed [here](#).

### Dementia Attitudes Monitor – Alzheimer's Research UK

Alzheimer's Research UK measure and track public perceptions, attitudes and behaviours around dementia and dementia research through the Dementia Attitudes Monitor and have published their latest findings from the 2018 survey in their latest research report. The aim of the research is to act as a catalyst for wider public dialogue and track public perceptions and attitudes towards dementia over time. The research found that overall; the public's awareness of dementia is relatively high however there is a misunderstanding of dementia as a disease, the risk factors associated with dementia and the ability for people to live a positive life after a diagnosis. The report highlighted that the public are keen to learn more about dementia and outlined the need to prioritise future dementia risk reduction messaging and education around dementia to break through the misconceptions and stigma.

### Dementia 2020 challenge: 2018 review phase 1

During 2018, stakeholders from the health and social care system, and the charitable sector, were asked to comment on the progress of the actions set out in the challenge on dementia 2020 implementation plan and what else is needed to be done to complete them. [This report summarises the responses and sets out revised actions for 2018 to 2020](#).

## What are we expecting to achieve? (Targets)

### National Ambitions

#### Dementia Diagnosis Rate

In 2015 NHS England set a national target for CCGs to diagnose at least two thirds (67.7%) of their expected local dementia population. Table 8 below shows that Wirral CCG has consistently met this target on a yearly basis since the introduction of the national dementia diagnosis ambition. More information can be found [here](#).

**Table 8:** Performance of expected dementia diagnoses, Wirral CCG, 2015 to 2018

Year	Number of patients >=65 on the Dementia Register	Diagnostic Rate	National Target
2015	3,022	69.2%	66.7%
2016	3,037	69.5%	66.7%
2017	3,195	72.8%	66.7%
2018	3,099	69.9%	66.7%

Source: NHS Digital

#### NHS Long Term Plan

Improving dementia care is also a key part of the [NHS Long Term Plan](#); with a focus made on improving care for those living with dementia whether they are in hospital or at home. The plan introduces an active focus on supporting people with dementia in the community through enhanced community multidisciplinary teams within primary and community hubs. These teams will comprise of a range of staff including GP's, pharmacists, district nurses and dementia workers and will be guided by the [NHS Comprehensive Model of Personal Care](#). Additionally, the NHS Long Term Plan emphasises the importance of working with the voluntary sector, including supporting the Alzheimer's Society to extend its [Dementia Connect](#) programme.

#### NHS Five Year Forward View

Dementia has been identified as one of the 10 priorities by NHS England as part of the [Five Year Forward View](#). NHS England aims to upgrade the quality of care and access to mental health and dementia services by increasing the proportion of people with a dementia diagnosis, offering a consistent standard of support for patients diagnosed with dementia and a commitment to promote dementia research and treatment. [The Next Steps on the NHS Five Year Forward View](#) report reiterates the commitment to diagnosis and post diagnostic support for people with dementia and their carers so that people can live independently in their own homes for longer, preventing crises and avoiding unnecessary admissions to hospital.

#### CCG Improvement and Assessment Framework (IAF) 2018/19

The [IAF](#) was introduced in 2016 and is designed to measure the success of CCG's in delivering the ambitions described in the Next Steps on the NHS Five Year Forward View to improve quality and outcomes for patients. Dementia is a key area in the IAF with the following indicators:

- Estimated diagnosis rate for people with dementia
- Dementia care planning and post-diagnostic support

#### Prime Ministers Challenge on Dementia 2020

In February 2015 the then Prime Minister, David Cameron, launched his [Challenge on Dementia 2020](#), which set out to build on the achievements of the Prime Minister's [Challenge on Dementia 2012-2015](#). It sets out NHS England's target that by 2020 we are:

- The best country in the world for dementia care and support for individuals with dementia, their carers and families to live; and
- The best place in the world to undertake research into dementia and other neurodegenerative diseases

Some of the key aspirations of this vision are:

- Improved public awareness and understanding of the risk factors linked to developing dementia
- Equal access to diagnosis for everyone
- GPs ensuring coordination and continuity of care for people with dementia
- Every person diagnosed with dementia having meaningful care following their diagnosis
- All NHS staff having received training on dementia appropriate to their role
- Increased numbers of people with dementia participating in research

Since then, the Challenge has been followed by an Implementation Plan which contains detailed steps that the government and other national bodies would have to take to improve the quality of life for people with dementia and their carers. These fell into four key themes:

- Risk reduction
- Health and care
- Dementia awareness
- Social action

### **[Join Dementia Research](#)**

The National Institute for Health Research ([NIHR](#)) in partnership with Alzheimer's Scotland, Alzheimer's Research UK and Alzheimer's Society have developed Join Dementia Research ([JDR](#)), a service which allows people to register their interest in participating in dementia research and be matched to suitable studies. As highlighted in the Prime Minister's Challenge on Dementia, research is vital in order to better understand the causes of dementia, develop effective treatments to improve care and to ultimately find a cure for dementia. The Wirral Memory Assessment Service, provided by Cheshire and Wirral Partnership NHS Foundation Trust (CWP), actively inform and direct people diagnosed with dementia to JDR as part of the post-diagnostic support pathway and are registered with JDR to conduct clinical trials on dementia.

### **Local Ambitions**

#### **[NHS Wirral CCG Operational Plan](#)**

The NHS England national dementia diagnosis target also features in [Wirral CCG's Operational Plan](#) 2017-2019 as a priority area alongside post-diagnostic care and support.

#### **[Healthy Wirral](#)**

[Healthy Wirral](#) aims to transform the way health and social care services are designed and delivered on Wirral to ensure that organisations are working as efficiently as possible and services empower patients to manage their own health and wellbeing. As part of the Healthy Wirral Plan, dementia has been identified as a key priority for the Mental Health Programme and aims to empower people with dementia to live enabling and fulfilling lives and receive the care and support they need. Key outcomes identified as part of this work stream include:

- Maintaining the current rate of dementia diagnosis
- Early detection and prevention
- Dementia friendly communities
- Carer support

**Wirral Dementia Strategy 2019-2022**

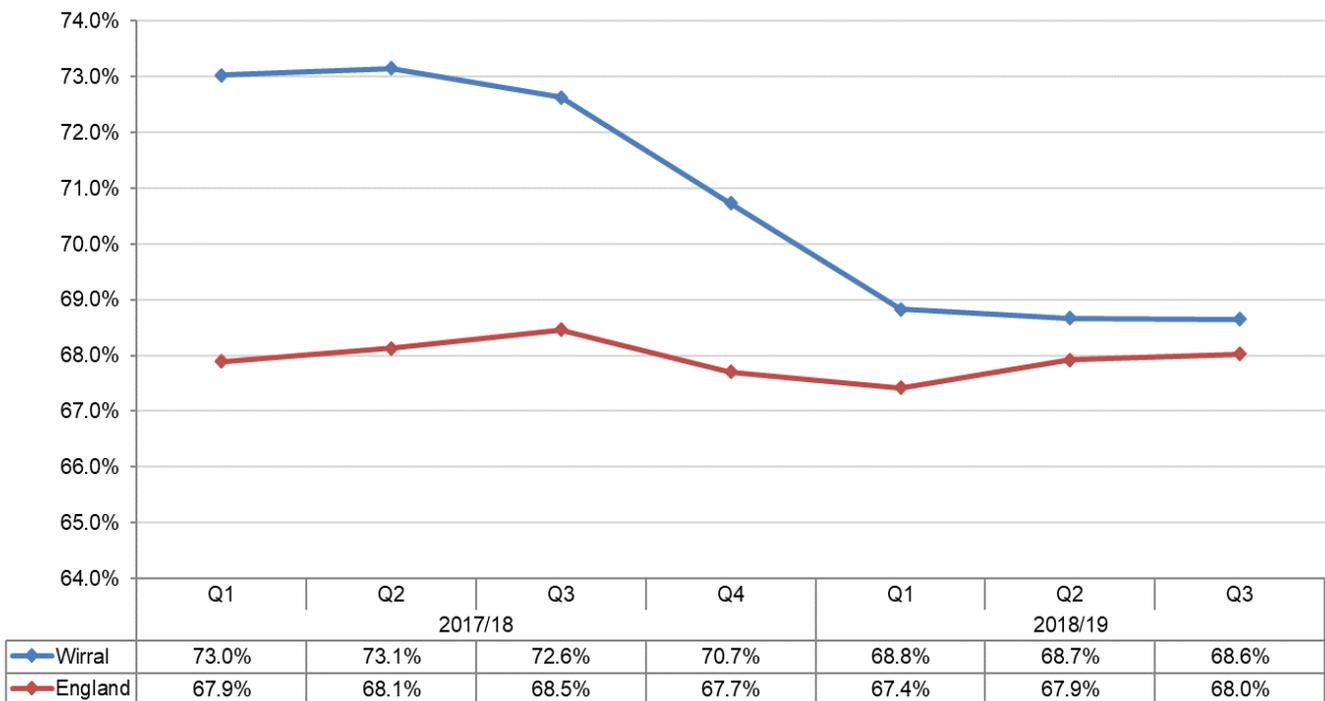
Wirral Health and Care Commissioning are currently in the process of refreshing the Wirral Dementia Strategy over the next four years. The local strategy will be structured around the national “[Well Pathway for Dementia](#)” and will focus on:

- Prevention and education
- Diagnosis and post diagnostic support for people with dementia and carers
- Collaborative working between statutory and voluntary sector organisations
- Supporting people to remain at home for as long as possible
- End of life care

**What are we achieving? (Performance)**

The estimated dementia diagnosis rate for those aged 65 and over Wirral is 68.6% as of Q3 (the average rate of October, November and December) for 2018/19. This means that Wirral is above the national rate of 68.0% for the same period. However, Wirral’s figures have shown a sharp decrease since Q1 (the average rate of April, May and June) of 2017/18 – from 73.0% to 68.6%. On the other hand, England has seen a slight increase in dementia diagnosis rates between Q1 of 2017/18 and Q3 of 2018/19 from 67.9% to 68.0%. Wirral has consistently performed better than England during this time.

**Figure 18:** Estimated Dementia Diagnosis Rate (Age 65+), by quarter, Wirral, and England



Source: [NHS Digital](#)

In 2018, Wirral was also awarded “Working to become dementia friendly” status. The Dementia Friendly Communities programme aims to meet the targets outlined by the Prime Minister’s Challenge on Dementia 2020 in order to create communities around the UK which make daily living and activities easier and more accessible to people living with dementia. It is from this initiative that in 2018, Wirral was awarded “Working to become dementia friendly” status. A full list of all communities across England and Wales can be found [here](#).

## What is this telling us?

Dementia continues to be a major contributor to the ill health of residents, with ongoing impact upon families and carers and a growing significant cost to local services and wider economy. Wirral has identified more people with dementia than the national average and continues to work towards improved and effective outcomes.

Albeit a positive picture in terms of action being undertaken to support improved awareness, diagnosis and the impacts on individuals and families are substantial and progress over time. Thus, local residents, including people living with dementia and their carers, must be involved in any service design or re-design as they are the experts by experience. Partner organisations, commissioners, service providers and local Dementia Strategy Group, must continue to gather the best evidence, information and insight to publish through Wirral Intelligence Service and Dementia JSNA so that decision making processes can be well informed.

## What are we doing and why?

In order to meet the challenge and impact upon our communities as a consequence of dementia, NHS Wirral CCG, Wirral Council and other partners are undertaking several approaches and actions in order to mitigate and improve outcomes for local residents. Amongst these are:

### [Wirral Dementia Strategy Board](#)

The purpose of the Dementia Strategy Board is to make Wirral a better place for people with dementia and their carers, through implementation of the Healthy Wirral Plan for Dementia and the local Dementia Strategy. The board is made up of representatives from both statutory organisations and non-statutory organisations. The board is responsible for ensuring alignment between a range of national and local programmes and initiatives that will support improved access, outcomes and experience for people affected by dementia.

### [Wirral Dementia Strategy 2019-2022](#)

In order to drive forward some of the recommendations outlined in national documentation, Wirral Health & Care Commissioning is refreshing the local strategy for Dementia for 2019-2022. The strategy will encompass health, social and community care aspirations for dementia care on Wirral in order to provide people with dementia and their carers the support needed to live well with dementia. Information gained from the Wirral Community Engagement exercise will inform the development of the strategy. The strategy is structured around the national "[Well Pathway for Dementia](#)" (image below) to ensure that every stage of an individual's dementia journey is address with a focus on:

- Prevention and education
- Diagnosis and post diagnostic support for people with dementia and carers
- Collaborative working between statutory and voluntary sector organisations
- Supporting people to remain at home for as long as possible
- End of life care

## NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 Risk of people developing dementia is minimised	 Timely accurate diagnosis, care plan, and review within first year	 Access to safe high quality health & social care for people with dementia and carers	 People with dementia can live normally in safe and accepting communities	 People living with dementia die with dignity in the place of their choosing
"I was given information about reducing my personal risk of getting dementia"	"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"	"I am treated with dignity & respect" "I get treatment and support, which are best for my dementia and my life"	"I know that those around me and looking after me are supported" "I feel included as part of society"	"I am confident my end of life wishes will be respected" "I can expect a good death"
<b>STANDARDS:</b> Prevention <sup>(1)</sup> Risk Reduction <sup>(5)</sup> Health Information <sup>(4)</sup> Supporting research <sup>(5)</sup>	<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>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>(5)</sup> Health & Social Services <sup>(5)</sup> Hard to Reach Groups <sup>(3)(5)</sup>	<b>STANDARDS:</b> Integrated Services <sup>(1)(3)(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>STANDARDS:</b> Palliative care and pain <sup>(1)(2)</sup> End of Life <sup>(4)</sup> Preferred Place of Death <sup>(5)</sup>
<small>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.</small>				

Source: [NHS England – The Well Pathway for Dementia](#)

### Wirral Dementia Action Alliance (DAA)

The aim of the Wirral DAA is to transform the quality of life of people with dementia and their carers by:

- Maintaining the status of 'Working to become a dementia friendly community' which was awarded to Wirral in 2018. Dementia friendly communities are an initiative ran by Alzheimer's Society. The aim of the scheme is to better support people with dementia and enable them to live well in the community. A dementia friendly community is a place where people with dementia are understood, respected, supported and confident they can contribute to community life
- Enabling people with dementia to be involved in activities that are meaningful to them
- Raising awareness of dementia across Wirral so people and services are dementia aware
- Facilitating and signposting people to care services which support people living with dementia and their carers
- Ensuring services are provided in a way that anticipates the needs of people living with dementia

The Wirral DAA are currently developing their action plan for the next 12 months and are looking to expand their membership to include more health, social care and community organisations. For more information on Wirral DAA including how to join, please visit the website at:

[https://www.dementiaaction.org.uk/local\\_alliances/15366\\_wirral\\_daa](https://www.dementiaaction.org.uk/local_alliances/15366_wirral_daa)

## Current activity and services

### Statutory Services

#### Wirral Memory Assessment Service

The Wirral Memory Assessment Service (WMAS) is a secondary care service that provides assessment for people who have been referred by their GP or other health and social care professions with suspected dementia or cognitive impairment. The service is responsible for diagnosing dementia, prescribing medication as appropriate and providing post-diagnostic support. The service is provided by Cheshire and Wirral Partnership NHS Foundation Trust (CWP) and is located at the Stein Centre, Birkenhead.

### **Dementia Liaison Service**

The Dementia Liaison Service is a secondary care service, provided by CWP, which offers a proactive, timely response to dementia specific mental health issues. The service offers a valid alternative to assessments in Accident and Emergency departments for people with dementia who may be in a crisis but who do not have a physical health problem. This service provides support to both the Older People's Assessment Unit (OPAU) based in Arrowe Park Hospital and to nursing and residential care homes (including 'transfer to assess' bed).

### **Local Enhanced Dementia Service**

In 2013/14, NHS Wirral CCG introduced the shared care model for dementia to support the Wirral Memory Assessment Service (WMAS) by sharing the management of dementia care with GP's. When a patient is diagnosed with dementia by the WMAS, a care plan is developed which may include being prescribed medication. Once an individual with dementia is stable on this treatment plan, they are discharged from the WMAS into the care of their GP who will act as a single point of contact. GP's are responsible for implementing regular medication reviews, supporting the person with dementia and their carer through the different stages of dementia and signposting to appropriate community services.

As part of the enhanced service specification, GP surgeries are required to identify a clinical lead for dementia who is responsible for supporting practice colleagues to develop their expertise and knowledge in working with patients with dementia and carers. The MAS also provides dementia training sessions for clinical practice staff, including GP's and practice nurses, on a quarterly basis which encompasses an overview of dementia and NICE treatment guidelines.

### **Nurse Practitioners for Older People (NPOP)**

NPOPs provide an outreach service to people living with dementia in their own homes. The service offers appropriate interventions to the individual diagnosed with dementia (depending on need), completion of cognitive assessments required to aid with referrals into the Memory Assessment Service, and signposting to other support services. NPOPs also offer advice to carers with regards to how they can access support to maintain their own health and wellbeing. Referrals to the NPOP team can be made via a GP and other health care professionals.

### **Department of Adult Social Services (DASS)**

The Department of Adult Social Services (DASS) integrated with the Wirral Community NHS Foundation Trust in June 2017. This integrated organisation is now known as Wirral Health and Care Community NHS Foundation Trust. Transferring social care staff to the NHS provides a more seamless service for patients and service users. The service provides domiciliary support, assistive technology support and support when people are being discharged from hospital.

### **North West Ambulance Service (NWS) NHS Trust**

NWAS is committed to improving the quality and care provided to dementia patients, with dementia identified as one of the key priority areas in the NWAS five-year plan. In April 2019, NWAS announced that over 6,000 staff are trained as "Dementia Friends". They have included dementia awareness sessions into their annual mandatory training package and all patient facing staff will receive classroom-based sessions to support them to provide the best care for people with dementia. NWAS are currently focusing on maximising links to local community services on Wirral in order to refer patients with dementia to the most appropriate services for their needs, such as falls prevention or social services, and to avoid hospital admissions wherever possible.

### **Merseyside Police**

Merseyside Police have adopted the national Herbert Protocol scheme, a simple risk reduction tool used in the event of an adult with care and support needs going missing. A loved one or carer can fill in the Herbert Protocol form with information about an individual, including a photograph of the person, and send this to Merseyside Police if the individual goes missing.

This is pertinent for people with dementia as they are at increased risk of going missing due to “walking about” or “wandering”. For more information on the Herbert Protocol and how to access the form, please visit the following link: <https://www.met.police.uk/herbertprotocol>.

### **Merseyside Fire and Rescue Service (MFRS)**

On Wirral, Merseyside Fire & Rescue Service are committed to supporting people with dementia and carers to live safe and well at home. As part of their Home Safety Assessment Scheme, MFRS conduct safe and well visits to thousands of over 65's each year to assess for fire safety and provide advice to people and carers. Staffs are trained in dementia awareness and are able to discuss extra support needs for people with dementia, such as recommending and providing heat alarms and fire-retardant bedding, or furniture covers.

### **Non-Statutory Services**

#### **Age UK Wirral**

Age UK Wirral provide day care centres for people with dementia and early onset dementia at Devonshire Resource Centre and Meadowcroft Community Wellbeing Hub. They also run various activities and events aimed at improving wellbeing of people with dementia and run the Carer Support Service. In collaboration with Dementia UK and Chapel House Dementia Resource Community, Age UK provide Admiral Nurses across Cheshire and Wirral. Admiral Nurses are registered nurses that provide specialist one-to-one support for people with dementia and their families experiencing challenges living with the condition with the aim of reducing the number of people with dementia in crisis. To find out more about Age UK Wirral then please visit the following link: <https://www.ageuk.org.uk/wirral/>

#### **Dementia Together Wirral (DTW)**

DTW run regular memory cafes and activities across various locations on Wirral for people with dementia and carers – including former carers. To find out more about DTW, how to become a volunteer and a timetable of events, please visit the following link:

<https://dementiatogetherwirral.org/>

#### **WIRED**

WIRED deliver a Carers Support Service for all unpaid carers on Wirral which provides information, advice and support via a carer's helpline, access to a carers grant for funding for health and wellbeing activities, carers emergency contact service, a counselling service for current and former carers and more. For further information, please visit the following link:

<http://www.wired.me.uk/>

#### **House of Memories**

A museum led dementia awareness programme which offers reminiscence activities for people with dementia and dementia training for carers and professionals. These activities take place across museums in Liverpool and the Lady Lever Art Gallery in Port Sunlight on Wirral.

#### **Forget Me Not Initiative**

In order to improve and make identification of people with dementia easier for health and care staff, the Forget Me Not Initiative has been launched on Wirral. As part of the initiative, stickers featuring the forget-me-not flower (the universally recognised symbol for dementia) are placed in homes, care homes and in hospital files to highlight to staff that the individual they are caring for has dementia and to prompt them to personalise their approach for that individual. The stickers have been shared with community nurses and social care staff on Wirral and will be continued to be rolled out to other health and care professionals to extend the reach of the initiative.

*Not all services and activities available on Wirral for people with dementia and listed here. For more information regarding the support services available in the community for people with dementia, please visit the local [Healthwatch Directory](#) and the [Live Well Directory](#).*

## What are the challenges?

### **Aging population and increasing prevalence of dementia**

As a consequence of advances in health care and technologies, people are living longer than ever. One of the outcomes of this improvement is that people are living longer which can result in an increase in age related conditions, including dementia. There are currently over 3200 people with a diagnosis of dementia on Wirral, with an estimated prevalence of 4500. This is set to rise to 7664 people living with dementia in Wirral by 2035 and as a result the demand on local health and social care services will increase. Therefore, there is a challenge on Wirral to develop a health and social care system that can meet these rising demands whilst providing quality pre- and post-diagnostic support for people with dementia and carers.

### **Stigma of dementia**

There is a continued need to raise the public's understanding of dementia in order to break down barriers and stigma associated with being diagnosed with the condition. By tackling public misconceptions, people with dementia will feel less isolated and more confident to live the life they want to lead without stigma and fear.

### **Parity of esteem**

It is acknowledged that nationally there is disparity between the quality and levels of care provided for physical health conditions compared with mental health conditions. A report from the [Alzheimer's Society](#) (2018) found that 49% of UK adults agreed that people with dementia experience worse care and support than people with other long term conditions such as cancer or heart disease. Additionally, dementia has higher health and social care costs (£11.9bn) than cancer (£5.0bn) and chronic heart disease (£2.5bn) combined ([Alzheimer's Research UK](#)).

### **Community Support**

Whilst Wirral is fortunate to have dedicated third sector organisations providing support for people with dementia and carers, there are gaps in provision in terms of the support offer in the community. The Wirral Dementia Engagement Report highlighted that post diagnostic support is the biggest gap in dementia care on Wirral with services being fragmented, sometimes duplicated, poorly advertised and under resourced. This was a view held by patients, carers, family members, friends and health and social care professionals.

### **Engaging with BAME and learning disability groups**

Currently there is little known about the prevalence and impact of dementia upon the BAME and learning disability populations on Wirral. Research tells us that dementia may be more common amongst Asian and Black Caribbean communities ([Parliamentary Group on Dementia, 2013](#)) and that 1 in 5 people with a learning disability over the age of 65 will develop dementia ([Alzheimer's Society, 2015](#)). More engagement is required with people from our BAME and learning difficulties population in order to raise awareness of the signs and symptoms of dementia, inform people about how people can access support (including obtaining a diagnosis), and how we can best tailor support to these groups.

### **Information sharing and data quality**

In order to provide comprehensive and effective support for people with dementia, better communication between statutory organisations is essential. Currently, due to Information Governance Regulations and complexities in NHS technology systems, there are barriers in place that prevent organisations sharing patient sensitive data. This can have a negative impact on the support a person with dementia receives in different health and social care services.

## Key gaps in knowledge and services

- More detailed information at borough level to inform local service design
- Gathering further public opinions on and around dementia to inform the JSNA and commissioning processes, particularly from Black, Asian and Minority Ethnic (BAME) communities, visually impaired, those with a learning disability and those from people who do not engage with services
- Enhanced post diagnostic support for people living with dementia (including carers and families)

## What is coming on the horizon?

### National and local ambitions

As outlined in the NHS long term plan the Wirral health and care system will increase focus on introducing community multidisciplinary teams aligned with new primary care networks to provide more care and support in the community for people living with dementia. This redesign of care will impact all stages of the dementia pathway, from improving waits for diagnosis, post diagnostic support in the community and offering more holistic person-centred care.

### Social Care Green Paper

In 2017 it was announced that there would be a social care Green Paper to explore how social care is funded and sustained for the long-term along with other topics including integration with health and other services, carers, workforce and technology. This document is likely to have a profound impact on the way that social care for people with dementia and carers is funded and implemented. The publication date of the Green Paper has been delayed on several occasions with no confirmed date at the time of writing.

## What does the research suggest as further actions?

- Continue to raise awareness of the risk factors related to dementia by supporting them to live healthier lives to reduce their risk of dementia
- Continuous improvement of post-diagnostic support including advice, information and guidance for people with dementia
- Continuous improvement of the support provided for carers of people with dementia.
- Development of community multidisciplinary teams supporting people with early onset dementia
- Continuous improvement of access to intermediate care for people with dementia
- Continuous improvement of the quality of hospital care for people with dementia including the pathway into and out of hospital
- Development of dementia case registers for the general population
- Consistent recording within all services of people who have dementia as a diagnosis
- Improved recording of learning disability in people who have dementia
- Improved recording of ethnic origin of people who have dementia as a diagnosis
- Ongoing workforce training to improve awareness and understanding of dementia and to improve the quality of assessment to increase the rate of detection and diagnosis
- Development of Dementia friendly communities in partnership with organisations outside of health and social care such as:
  - Local businesses (supermarkets, shopping centres, banks, restaurants etc.)
  - Faith organisations
  - Transport services
  - Housing organisations

- Provide more opportunities for people with dementia and their carers to get involved in dementia research and encourage organisations to signpost to [Join Dementia Research](#) to support the development of treatments for dementia

## Key content

## Links

### Alzheimer's Society

Alzheimer's Society is the only UK charity that campaigns for change, funds research to find a cure and supports people living with dementia today: <https://www.alzheimers.org.uk/about-dementia/types-dementia/what-dementia>

### Evidence in Mind, Dementia Bulletin (Merseycare NHSFT)

Evidence in Mind is a website containing resources for mental health evidence in 5 areas; dementia, depression, learning disabilities, suicide prevention and current bytes - <http://www.evidenceinmind.co.uk/services/bulletins/>

### Dementia UK

Dementia UK provides specialist dementia support for families through their Admiral Nurse service: <https://www.dementiauk.org/>

## Relevant and related National and local strategies

Please see related national and local strategies [here](#)

## References

Please see references [here](#)

## Appendix

Please see appendix [here](#)

## Contact details

### For further details please contact:

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