1 Five key points

1. It is estimated that around 13,000 Suffolk residents (including those with and without a diagnosis) were living with dementia in 2018. (3.1 Prevalence)

2. It is estimated that around 4,130 individuals in Suffolk are living with undiagnosed dementia. (3.1 Prevalence)

3. It is projected that the number of people living with dementia will increase to around 23,000 by 2040. This increase is driven by the ageing population – dementia is more common among older people, in particular females aged over 75. (3.1 Prevalence)

4. Research has identified a decreased dementia risk for people who have better heart health. Regular exercise, a healthy diet, not smoking, and controlling weight, blood pressure, cholesterol, and blood sugar are all associated with a lower risk of dementia. (2 Why is dementia important?)

5. The proportion of deaths attributed to dementia and Alzheimer’s disease in Suffolk has increased over the last decade. In 2008, 1 in 30 male deaths and 1 in 15 female deaths were attributed to dementia and Alzheimer’s disease. By 2017, nearly 1 in 10 male deaths and 1 in 6 female deaths were attributed to dementia and Alzheimer’s disease. (3.4 Mortality)
2 Why is dementia important in Suffolk?

The term ‘dementia’ describes a set of symptoms that include loss of concentration and memory problems, mood and behaviour changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, such as Alzheimer’s disease; a series of small strokes; or other neurological conditions such as Parkinson’s Disease. Around 60% of people with dementia have Alzheimer’s disease, which is the most common type of dementia, around 20% have vascular dementia, which results from problems with the blood supply to the brain, and many people have a mixture of the two.[21]

Dementia is a progressive condition, which means that the symptoms become more severe over time. People with dementia and their families have to cope with changing abilities such as the capacity to make decisions about major life events as well as day-to-day situations. The reality for many people with dementia is that they will have complex needs compounded by a range of co-morbidities. A survey by Alzheimer’s Society found that almost three quarters (72%) of respondents were living with another medical condition or disability as well as dementia. The range of conditions varied considerably, but the most common ones were arthritis, hearing problems, heart disease or a physical disability.[1]

Of all diseases, cancer remains the most common cause of death in the UK (accounting for 28.1% of all deaths registered in 2017).[2] Looking at causes of death in more detail, illnesses such as cancer and circulatory diseases can be split into different subtypes, with the aim to provide policy-makers with enough detail to generate appropriate health advocacy and interventions. At this more detailed level, dementia and Alzheimer’s disease are the leading cause of death in England and Wales, accounting for one in eight (12.7%) of all deaths registered.[2]

The number of older people in Suffolk will continue to increase over the coming decades. In 2016, one in five Suffolk residents were aged 65 or over; this will rise to one in three by 2041. The number of people aged 85 or over will more than double in the same time period.[3] These longer lives are, of course, a success story in very many ways; but as people live longer, many more people will develop dementia and will need access to efficient and effective interventions and support.

Dementia has a significant impact on the quality of life of those living with the condition and the family and friends who care for them. It is a complex condition which can cause extensive physical, psychological, emotional and financial stresses to individuals living with dementia, their family carers and the wider community.

Although age is the largest risk factor for dementia, the condition is not an inevitable part of getting older and there are things we can all do to help reduce our risk. Research has identified a decreased dementia risk for people who have better heart health; regular exercise, a healthy diet, not smoking, and controlling weight, blood pressure, cholesterol, and blood sugar were all associated with a lower risk of dementia.[4] As well as these seven aspects of healthy living, drinking within recommended guidelines and staying mentally active and socially engaged have also been linked to better brain health in later life.[5]
3 What is the local picture?

Note that Suffolk is covered by three Clinical Commissioning Groups (CCGs) and one of them spans Suffolk and Norfolk (Great Yarmouth and Waveney CCG). Figures are presented at CCG level because the data cannot be disaggregated into Great Yarmouth and Waveney.

3.1 Prevalence

The true number of people with dementia in Suffolk is unknown because there are a certain number of people who live with the condition but have not been formally diagnosed. However, it is possible to estimate the number of people with dementia in Suffolk.

The prevalence estimate is calculated by applying national prevalence estimates from the Dementia UK Report to Office of National Statistics population projections.[3],[6] Using 2016 population figures, it is estimated that in 2018 there were around 13,000 people with dementia living in Suffolk. The number of individuals with dementia increases with age. The number of dementia sufferers is higher among women than men among those aged 75 and over (Figure 1).

Using the same method of applying national prevalence estimates to population projections, it is estimated that by 2040 there will be around 23,000 individuals living with dementia in Suffolk. The increase is driven by the ageing population and prevalence estimates are particularly high among those aged 85 and over.

Figure 1: Estimated number of people living with dementia by gender and age band, Suffolk, 2018[3],[6]


3.2 Gap between expected and actual dementia diagnoses

Not everyone with dementia has a formal diagnosis. The difference between the number of people thought to have dementia and the number of people diagnosed with dementia is
known as the “dementia gap”. The nationally set target is for at least two thirds of people with dementia to be diagnosed.\[7\]

Dementia diagnosis rates are calculated by comparing the number of GP registered people with a diagnosis of dementia and the number of people expected to have dementia. In August 2018, the dementia diagnosis rate among people aged 65 and over in Suffolk was 64.5%, which is slightly below the national target although the difference is not statistically significant. The highest dementia diagnosis rates were found in Ipswich (73.7%) and Babergh (69.2%); the lowest are found in Waveney (58.3%) and Forest Heath (60.3%) (Figure 2).\[8\]

The estimated number of people with dementia varies by district, based on the age and gender of the population. The highest estimated number of individuals with dementia live in Waveney (2,270). The large estimated number of people with dementia and a low diagnosis rate combine to result in an estimated 950 individuals in Waveney with undiagnosed dementia. In total across Suffolk it is estimated that 4,130 individuals have undiagnosed dementia.

Figure 2: Number of individuals diagnosed with dementia, number estimated to be undiagnosed and diagnosis rate, districts and boroughs, Suffolk, August 2018 [8]


3.3 Hospital admissions
In the tables below, dementia has been separated into Alzheimer’s disease and vascular/unspecified dementia.

People with dementia can be admitted to hospital because of their dementia or for a different medical problem. Nationally, only 1 in 20 (5.2%) admissions are related to dementia, with the other 19 in 20 (94.8%) being primarily related to a different condition.\[9\] The following tables only correspond to admissions which a primarily related to dementia.

The numbers of people admitted to hospital primarily because of their dementia are low. The age-sex standardised hospital admission rate for Alzheimer’s disease was comparable in
West Suffolk CCG, Ipswich and East Suffolk CCG and Great Yarmouth and Waveney CCG to the East of England (Table 1).[10]

Table 1: Age-sex standardised hospital admission rate per 100,000 registered patients/residents for Alzheimer’s disease, CCGs, East of England, England, 2017/18[10]

<table>
<thead>
<tr>
<th>Geographical area</th>
<th>Hospital admission rate per 100,000 registered patients/residents</th>
<th>RAG compared to East of England</th>
<th>Number of admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ipswich and East Suffolk CCG</td>
<td>5.8</td>
<td></td>
<td>25</td>
</tr>
<tr>
<td>Great Yarmouth and Waveney CCG</td>
<td>9.0</td>
<td></td>
<td>30</td>
</tr>
<tr>
<td>West Suffolk CCG</td>
<td>5.3</td>
<td></td>
<td>15</td>
</tr>
<tr>
<td>East of England</td>
<td>8.2</td>
<td></td>
<td>515</td>
</tr>
<tr>
<td>England</td>
<td>9.7</td>
<td></td>
<td>4,985</td>
</tr>
</tbody>
</table>

Notes: CCG admission rates calculated per 100,000 registered patients; East of England and England admission rates calculated per 100,000 residents; RAG calculated using 95% confidence interval.


In Suffolk, more than twice as many people were admitted to hospital with vascular and unspecified dementia compared to Alzheimer’s disease, despite Alzheimer’s disease being three times more common. One potential reason could be that people with vascular dementia are more likely to have co-existing medical problems such as diabetes and heart disease, than people with Alzheimer’s disease.[11]

The age-sex standardised hospital admission rate for vascular and unspecified dementia was significantly lower in West Suffolk CCG compared with the East of England, whereas it was comparable in Ipswich and East Suffolk CCG and Great Yarmouth and Waveney CCG (Table 2).[10]

Table 2: Age-sex standardised hospital admission rate per 100,000 registered patients/residents for vascular and unspecified dementia, CCGs, East of England, England, 2017/18[10]

<table>
<thead>
<tr>
<th>Geographical area</th>
<th>Hospital admission rate per 100,000 registered patients/residents</th>
<th>RAG compared to East of England</th>
<th>Number of admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ipswich and East Suffolk CCG</td>
<td>18.2</td>
<td></td>
<td>85</td>
</tr>
<tr>
<td>Great Yarmouth and Waveney CCG</td>
<td>12.7</td>
<td></td>
<td>40</td>
</tr>
<tr>
<td>West Suffolk CCG</td>
<td>9.7</td>
<td></td>
<td>30</td>
</tr>
<tr>
<td>East of England</td>
<td>14.4</td>
<td></td>
<td>925</td>
</tr>
<tr>
<td>England</td>
<td>16.3</td>
<td></td>
<td>8,465</td>
</tr>
</tbody>
</table>

Notes: CCG admission rates calculated per 100,000 registered patients; East of England and England admission rates calculated per 100,000 residents; RAG calculated using 95% confidence interval.


3.4 Mortality

Nationally, age-standardised mortality rates (ASMRs) for four of the top five leading causes of death have generally been decreasing since 2001.[2] In contrast, ASMRs for both dementia
and Alzheimer’s disease have been increasing in recent years among both males and females.

The proportion of deaths attributed to dementia and Alzheimer’s disease in Suffolk has increased over the last decade (Figure 3). In 2008, 1 in 30 (3.3%) male deaths and 1 in 15 (6.9%) female deaths were attributed to dementia and Alzheimer’s disease.[10] By 2017, nearly 1 in 10 (9.0%) male deaths and 1 in 6 (6.9%) female deaths were attributed to dementia and Alzheimer’s disease. Potential factors influencing the increase were awareness among the wider population and accuracy of death certificate coding by clinicians. While recording of dementia on death certificates has improved significantly, it is still thought that this information provides an underestimate of the true impact of dementia across England and Wales.[12]

![Figure 3: Proportion of deaths attributed to dementia and Alzheimer’s disease, Suffolk, 2008-2017](10)

In 2017/18, the age-sex standardised mortality rate from Alzheimer’s disease in Ipswich and East Suffolk CCG was higher than the East of England rate. The reason for this is not clear, although it could be related to greater accuracy of death certificate coding by clinicians in this area. In Great Yarmouth and Waveney CCG and West Suffolk CCG the rate was comparable to the East of England (Table 3).[10]

<table>
<thead>
<tr>
<th>Geographical area</th>
<th>Mortality rate per 100,000 registered patients/residents</th>
<th>RAG compared to East of England</th>
<th>Number of deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ipswich and East Suffolk CCG</td>
<td>38.0</td>
<td>Red</td>
<td>184</td>
</tr>
<tr>
<td>Great Yarmouth and Waveney CCG</td>
<td>25.4</td>
<td>Yellow</td>
<td>83</td>
</tr>
<tr>
<td>West Suffolk CCG</td>
<td>28.9</td>
<td>Yellow</td>
<td>88</td>
</tr>
<tr>
<td>East of England</td>
<td>26.3</td>
<td>Yellow</td>
<td>1,727</td>
</tr>
<tr>
<td>England</td>
<td>28.5</td>
<td>Red</td>
<td>15,157</td>
</tr>
</tbody>
</table>
Notes: CCG mortality rates calculated per 100,000 registered patients; East of England and England mortality rates calculated per 100,000 residents; RAG calculated using 95% confidence interval.


In 2017/18, the age-sex standardised mortality rate from vascular and unspecified dementia in Ipswich and East Suffolk CCG, Great Yarmouth and Waveney CCG and West Suffolk CCG were all comparable to the East of England rate (Table 4).

Table 4: Age-sex standardised mortality rate per 100,000 registered patients/residents from vascular and unspecified dementia, CCGs, East of England, England, 2017/18

<table>
<thead>
<tr>
<th>Geographical area</th>
<th>Mortality rate per 100,000 registered patients/residents</th>
<th>RAG compared to East of England</th>
<th>Number of deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ipswich and East Suffolk CCG</td>
<td>72.6</td>
<td></td>
<td>352</td>
</tr>
<tr>
<td>Great Yarmouth and Waveney CCG</td>
<td>83.3</td>
<td></td>
<td>263</td>
</tr>
<tr>
<td>West Suffolk CCG</td>
<td>81.4</td>
<td></td>
<td>234</td>
</tr>
<tr>
<td>East of England</td>
<td>79.8</td>
<td></td>
<td>5,141</td>
</tr>
<tr>
<td>England</td>
<td>84.3</td>
<td></td>
<td>44,236</td>
</tr>
</tbody>
</table>

Notes: CCG mortality rates calculated per 100,000 registered patients; East of England and England mortality rates calculated per 100,000 residents; RAG calculated using 95% confidence interval.


4 What policies affect dementia?

The National Institute of Health and Care Excellence (NICE) have published guidelines covering mid-life approaches to delay or prevent the onset of dementia in later life, and diagnosis and management of dementia (including Alzheimer’s disease).

The 2014 Care Act gives carers the right to a needs assessment, and entitles carers to support if they meet the eligibility criteria. Given how important carers are for many people with dementia, and the evidence that caring for someone with dementia can be detrimental to the carer’s health, these statutory duties should have positive consequences for people with dementia and their carers.

In 2015 a second Prime Minister’s Challenge (“Dementia 2020”) was launched, which sets out a number of improvement aspirations to be met by 2020. These wide ranging aspirations include greater awareness of the risk factors for dementia, improved diagnosis rates and greater support for carers. The Dementia 2020 ambitions have been included in the NHS Planning Guidance 2016/17 – 2020/21, which states that by 2020 there should be a measurable improvement in all areas, including maintaining a diagnosis rate of at least two thirds and improving the quality of post-diagnosis treatment and support for people with dementia and their carers.

As part of its Joint Health and Wellbeing Strategy priority of focussing on the quality of life of older people, the Suffolk Health and Wellbeing Board became a Strategic Dementia Alliance in January 2015. The Health and Wellbeing Board also provides ongoing leadership across Suffolk in the development of Dementia Friendly Communities. Member organisations...
of the Health and Wellbeing Board have also undertaken to increase their staff’s dementia awareness levels and have provided development and learning sessions to facilitate this.

Suffolk has seen an increase in activity to support people affected by dementia and their family carers. Several Dementia Action Alliances are registered across the county, including in Stowmarket, Felixstowe, Needham Market, Haverhill, Hadleigh, Newmarket and the long-standing Debenham Project. The benefits of local action include: local solutions that are devised for, and by, local people; the development of community capacity and connections that benefit the wider community.

The evidence around cost effectiveness of different interventions for dementia is covered in detail in the 2016 update of the Suffolk Dementia Needs Assessment. It should be noted that, although some interventions are cost effective, there are issues with budgetary crossover in which investment is made in the health budget which leads to savings in social care. Closer working relationships between health and social care organisations should make this less problematic in the longer term.

5 Further information

The Prime Minister’s Challenge on Dementia 2020 was set up in 2015 by the previous Government. The current Government has recommitted to the Challenge. By 2020, the Challenge aims for England to become:

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

There are several charities whose focus is on dementia or Alzheimer’s disease, including Dementia UK, Alzheimer’s Research UK and Alzheimer’s Society. The organisations all provide information about dementia and support to sufferers. Alzheimer’s Research UK is a good source of quantitative data about dementia:

- [www.dementiauk.org/](http://www.dementiauk.org/)
- [www.alzheimersresearchuk.org/](http://www.alzheimersresearchuk.org/)
- [www.alzheimers.org.uk/](http://www.alzheimers.org.uk/)

Join Dementia Research is a service which allows people to register their interest in participating in dementia research and be matched to suitable studies. This service, which aims to connect researchers with people who want to participate in studies, is run by the National Institute for Health Research (NIHR). [www.joindementiaresearch.nihr.ac.uk/](http://www.joindementiaresearch.nihr.ac.uk/)

Dementia Action Alliance is an alliance for organisations across England to connect, share best practice and take action on dementia. The alliance’s aim is to bring together leading organisations across England committed to transforming health and social care outcomes for people affected by dementia. [www.dementiaaction.org.uk/](http://www.dementiaaction.org.uk/)

Dementia Together is a service which provides practical information and support for people who are curious, concerned or living with dementia, their carers and healthcare professionals. It is available to anyone living in Suffolk and Waveney. [www.dementia-together.com/](http://www.dementia-together.com/)
6 References


