

Dementia

Introduction

Dementia is a term that covers a wide range of medical conditions including Alzheimer's. The disorders grouped under "dementia" are caused by abnormal brain changes which can cause loss of memory, problem-solving, language and other cognitive abilities which are severe enough to interfere with daily life and independent living¹.

Dementia is predicted to increase by 55% in England between 2020 and 2040, meaning that by 2040 there will be 1.15 million people in England living with dementia². National models also suggest that there will not only be increases in the number of people living with dementia but also an increased complexity of care needs³. In the UK, it has been found that two thirds of people accessing homecare and 70% of care home residents live with some form of dementia⁴. Hospitals have experienced 29% increases in the number of emergency admissions of older patients (65+) between 2011 and 2018 and older patients are known to account for approximately 68% of total bed days spent in hospital⁵. Promoting active and healthy ageing is essential to reduce the time spent in ill health as much as possible.

Costs for dementia care in the UK are made up of healthcare costs and social care costs, but a large proportion care is unpaid through family and friends. The total cost of dementia in the UK is currently estimated to be £34.7 billion a year, with social care (publicly and privately funded) making up the largest proportion of this at £15.7 billion⁶ and health care accounting for 14% (£4.9 billion) of the total costs in the UK. With a population that is aging, the numbers of people with dementia are projected to increase in society and services will need to adapt accordingly. In the absence of any new cures or interventions, earlier diagnosis and provision of appropriate support will ensure that people with dementia will have more choice and control over how they live, enabling them to live independently for longer.

Summary

With an increased proportion of the population living longer, the number of people living with dementia is expected to increase. By 2030 it is estimated that about 21,400 people in Norfolk and Waveney will have dementia. Patients who have dementia are more likely to experience many more complications and stay longer in hospital than those without dementia⁷.

The strongest known risk factor for dementia is age, whilst it is not possible to delay getting older there are several lifestyle choices that can reduce the risk of dementia⁸. Regular physical exercise, drinking alcohol in moderation (if at all) and not smoking combined with a healthy weight and diet are all known to reduce the risk of dementia. Area level factors such as urban/rural settings and deprivation have also been associated with variation in local services and resources impacting on a person's capability to live well with dementia⁹. It has also been found that lower wealth later in life is associated with an increased risk of dementia, indicating that people with fewer financial resources are at a higher risk¹⁰.

¹ <https://www.alz.org/alzheimers-dementia/what-is-dementia>

² www.poppi.org.uk

³ Kingston A, Comas-Herrera A, Jagger C, Forecasting the care needs of the older population in England over the next 20 years: estimates from the Population Ageing and Care Simulation (PACSim) modelling study. *Lancet Public Health*. 2018; **3**: e447-e455

⁴ <https://www.alzheimers.org.uk/sites/default/files/2018-05/Dementia%20the%20true%20cost%20-%20Alzheimers%20Society%20report.pdf>

⁵ https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/older-people-and-emergency-bed-use-aug-2012.pdf

⁶ https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

⁷ <https://www.alzheimers.org.uk/get-involved/our-campaigns/fix-dementia-care-hospitals-statistics>

⁸ https://www.alzheimers.org.uk/sites/default/files/pdf/factsheet_risk_factors_for_dementia.pdf

⁹ Cromarty H. Adult Social Care Funding (England). House of Commons Library, 2017

¹⁰ Cadar, D., Lassale, C, Davies, H., *et al.* Individual and Area-Based Socioeconomic Factors Associated With Dementia Incidence in England. Evidence From a 12-Year Follow-up in the English Longitudinal Study of Ageing. *JAMA Psychiatry*. 2018;**75(7)**:723-732

Early diagnosis of dementia means that people have improved access to support and treatment which can help promote independent living for longer within society. Comparing observed numbers of people with dementia to the numbers expected at a GP practice level gives an indication of the number of people living with dementia that are undiagnosed. Across Norfolk it is estimated that 63% of people with dementia have been diagnosed.

Dementia remains a top priority for Norfolk Health and Wellbeing Board and has been championed by a series of partnership groups over the years. In Norfolk, there are numerous services available for people living with dementia. However, as dementia prevalence increases and diagnosis rates improve, potentially more of these support services will need to be available.

Population, risk factors and outcomes related to dementia pathway

Researchers are still investigating how dementia develops and there is no certain way to prevent all types of the group of syndromes. However, there is strong evidence that adopting a healthy lifestyle can reduce your risk of developing dementia in later life. Several dementia risk factors are difficult or impossible to change, such as¹¹:

- Age: Although it is possible to get dementia at any age, most cases occur in those aged over 65, with the risk then roughly doubling every 5 years. As life expectancy increases, the number of older people, including those living with dementia, is increasing¹². There is a one in six chance of developing dementia over the age of 80.
- Ethnicity: African, African-Caribbean and South Asian communities appear at a higher risk of developing dementia than white Europeans, although specific environmental risk factors are thought to explain this.
- Gender: Women diagnosed with dementia outnumber men two to one.
- Genetics: Genetics alone rarely cause dementia, although when this does occur it usually affects people aged under 65 years of age.
- Levels of education: Low educational attainment has been linked with dementia.

It is widely recognised by experts in the field that what is good for the heart is also good for your brain including¹³:

- Stopping smoking
- Keeping alcohol intake within recommended limits
- Eating a healthy and balanced diet
- Exercising regularly
- Maintaining a healthy weight
- Keeping blood pressure at a healthy level.

There are different types of dementia which affect people differently, however common early symptoms which tend to appear some time before a formal diagnosis include memory loss, mood changes, difficulty concentrating, being confused about time and place and finding it difficult to carry out familiar daily tasks. These symptoms are mild to begin with and tend to get gradually worse eventually impacting on ability to maintain independence and carry out everyday activities¹⁴.

Development and publication of a 5-year transformation plan known as the 'Well Pathway for Dementia' has been produced by the NHS¹⁵. The outcomes related to the dementia pathway in Norfolk are summarised in Figure 1. This is now the framework upon which we measure the dementia metrics against and is set out as follows:

- Preventing well: Risk of people developing dementia is minimised.
- Diagnosing well: Timely accurate diagnosis, care plan and review within the first year.
- Supporting well: Access to safe, high quality health and social care for people with dementia and carers.
- Living well: People with dementia can live normally in safe and accepting communities.
- Dying well: People with dementia die with dignity in the place of their choosing.

¹¹ <https://www.dementiauk.org/understanding-dementia/prevention-and-risk-factors/>

¹² [Dementia prevention, intervention, and care: 2020 report of the Lancet Commission - The Lancet](https://www.thelancet.com/commission/2020)

¹³ <https://www.nhs.uk/conditions/dementia/dementia-prevention/>

¹⁴ <https://www.nhs.uk/conditions/dementia/symptoms/>

¹⁵ <https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf>

Norfolk JSNA Briefing Document

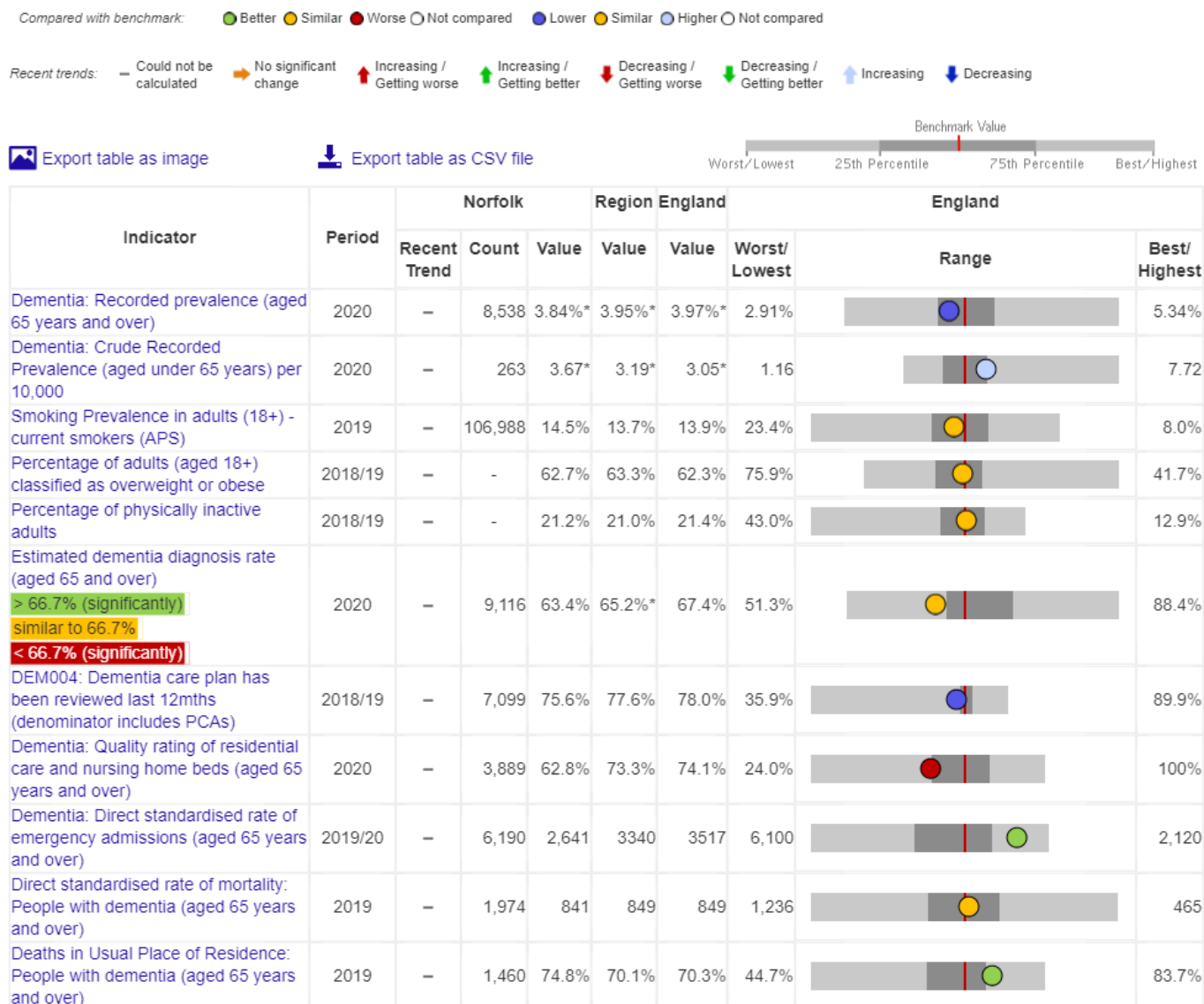


Figure 1. Public Health England dementia pathway summary for Norfolk¹⁶

During the 2018-2019 financial year, there were 6,190 emergency hospital admissions for people aged over 65 with a comorbidity of dementia across Norfolk, the equivalent of 2,641 per 100,000, this is significantly better than the national average. Across Norfolk about 10% of admissions have a comorbidity of dementia, this is in line with the East of England.

Recorded dementia prevalence for those aged 65+ is 3.84% (8,538 people) which is significantly lower than the England average of 3.97% (Fig.1). The crude recorded prevalence of dementia in those aged under 65 is significantly higher than England at 3.67 per 10,000. There are numerous risk factors which could affect your chances of getting dementia, some of these such as age and genetics cannot be changed. However, research reported at the Alzheimer's Association International Conference in 2019 suggested that regular exercise, a healthy diet, not smoking and regular cognitive stimulation may decrease the risk of dementia¹⁷. The percentage of adults significantly overweight or obese, smoking prevalence and proportion of physically inactive adults are not significantly different in Norfolk compared to England (Fig.2). However, compared to the national average, Norfolk has significantly higher stroke (all ages), hypertension (all ages) and diabetes prevalence (17+) (Fig.2). Excessive alcohol consumption is known to increase your risk of stroke and heart disease, Norfolk has a statistically higher number of admission episodes for alcohol-related conditions

¹⁶<https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data#page/1/gid/1938133052/pat/6/par/E12000006/ati/202/are/E10000020/cid/4/page-options/ovw-do-0>

¹⁷ https://www.alz.org/aaic/releases_2019/sunLIFESTYLE-jul14.asp

(narrow) for people aged between 40 and 64 years. This suggests that the demand that will be placed on the system in Norfolk by dementia, combined with the aging population is likely to be higher than for other parts of the country where the number of older people is less and prevalence of risk factors is lower.

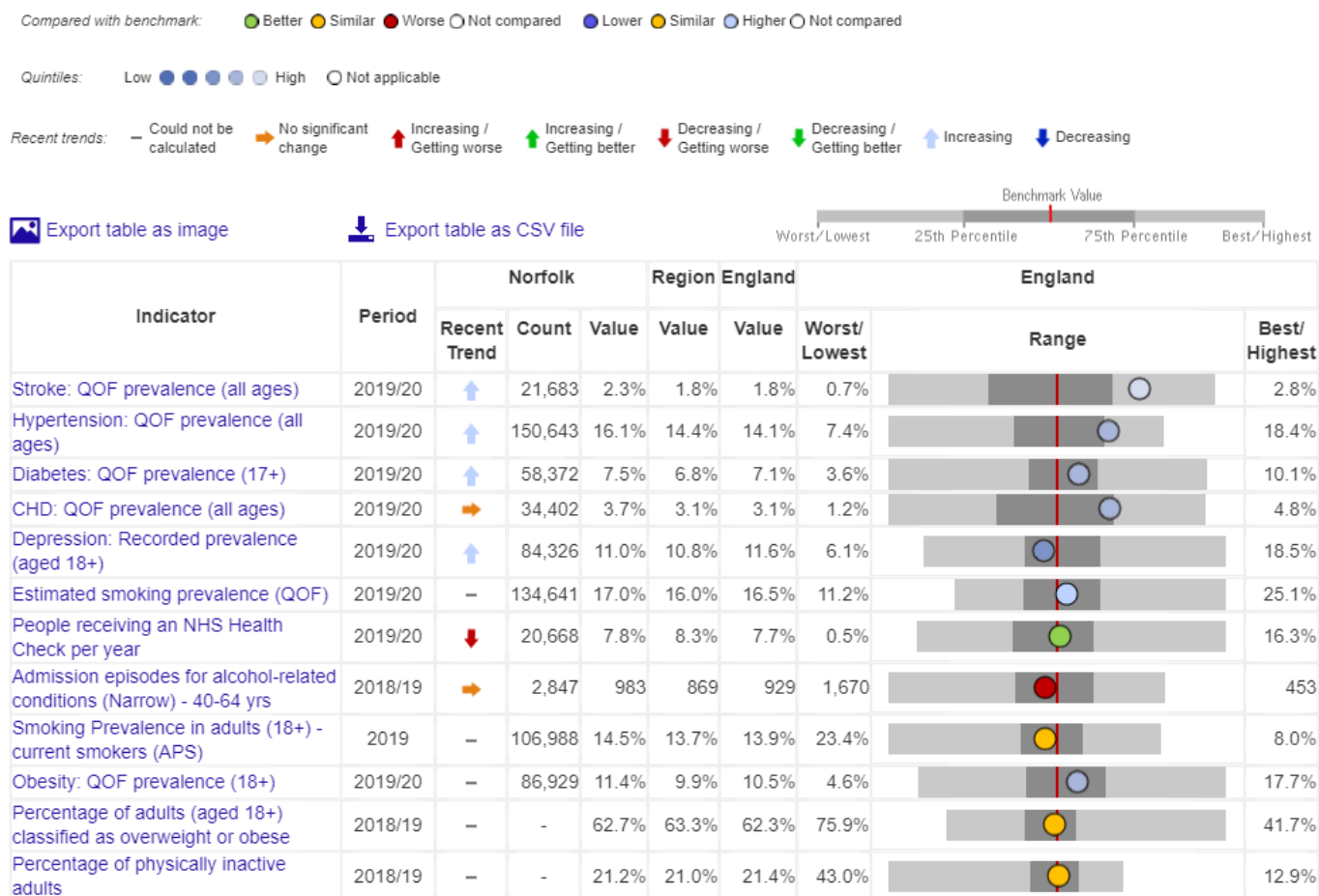


Figure 2. Dementia prevention pathway for Norfolk benchmarked against the national average (Fingertips).

Burden of ill health and gaps in services

About 1% of the population in Norfolk have a dementia diagnosis recorded and this is higher than in England as a whole, most likely due to the ageing population in the county. By 2030 dementia prevalence is expected to increase to about 21,400 people (Figure 3). Figure 3 shows the current estimated diagnosed and undiagnosed dementia cases and the forecasted cases for 2030 based on age and gender projections. This shows that between 2019 and 2030, there will be an estimated 28.4% increase in people living with dementia in Norfolk. People living with dementia get the diagnosis and medication from the NHS, however often the symptoms mean that they need help with everyday living such as personal care and shopping meaning that social care also provides a lot of support to people living with the condition¹⁸. As such a higher number of dementia cases in Norfolk will put additional demand on both the health and social care services required to provide treatment and support to enable the individuals to live well for longer.

¹⁸ <https://www.alzheimers.org.uk/sites/default/files/2018-05/Dementia%20the%20true%20cost%20-%20Alzheimers%20Society%20report.pdf>

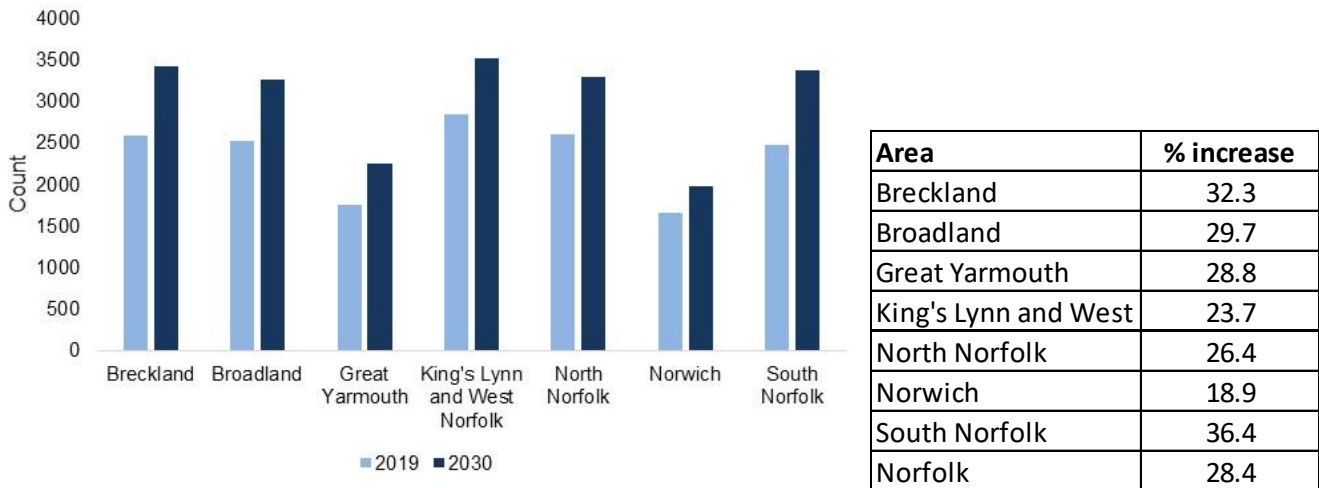


Figure 3. Projected dementia prevalence by district between 2019 and 2030. Table shows the percentage increase for this period.

A commitment to increase the number of people living with dementia to have a formal diagnosis was introduced in 2012 as one of the Prime Minister’s challenge for dementia. The rationale for this objective was that a timely diagnosis improves the outcome of the people living with the disease and enables both their carers and healthcare staff to plan accordingly and better work together to improve the health and care outcomes of the individual¹⁹. In 2019/20 there were about 10,796 people registered at practices in Norfolk and Waveney with dementia diagnosed. For districts within Norfolk the area with the highest number of people diagnosed with dementia is Breckland with almost 1,600 people, about 70% of the expected number of people with dementia (Fig.4 & Fig. 5). Three districts in Norfolk; South Norfolk, North Norfolk and King’s Lynn and West Norfolk, are known to have significantly worse dementia diagnosis rates than the national average of 67% (Fig.4).

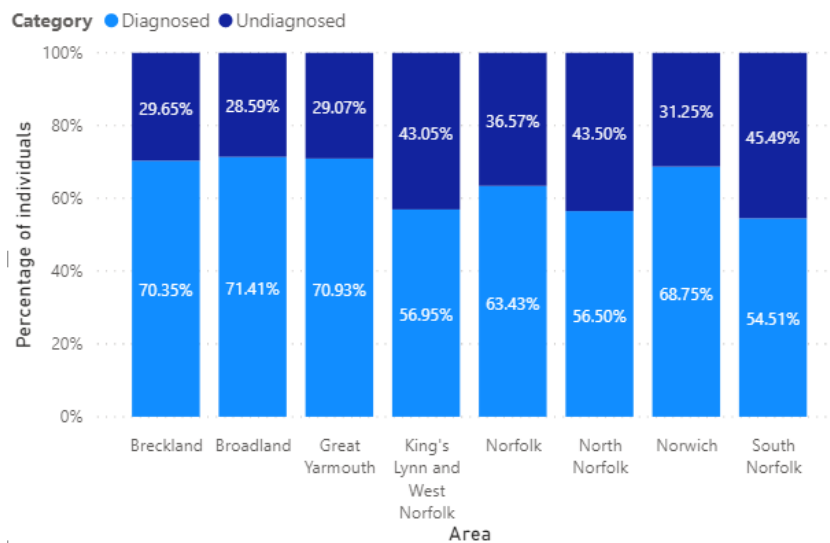


Figure 4. Estimated dementia diagnosis rate (aged 65+), Norfolk districts (March 2020)²⁰.

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https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf

20 [Recorded Dementia Diagnoses - March 2020 - NHS Digital](#)

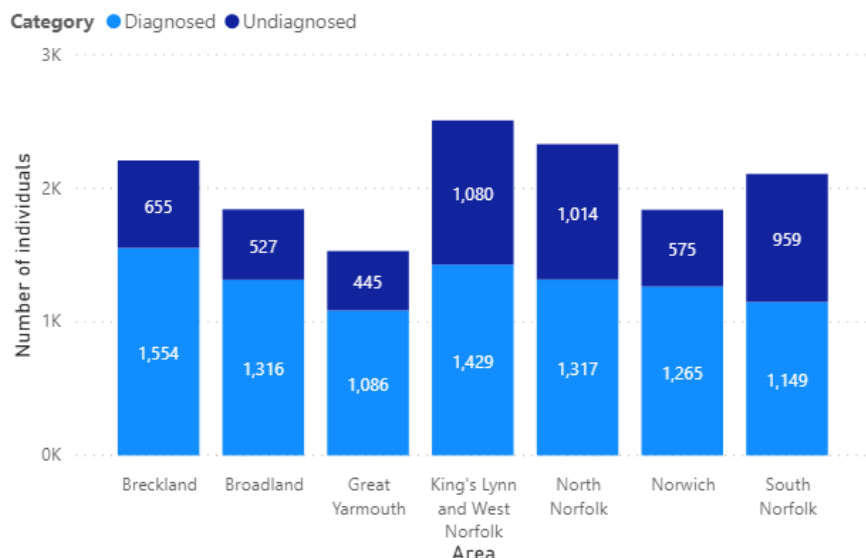


Figure 5. Estimated prevalence of dementia by district (March 2020).

Further demand is placed on services if people need to be admitted to hospital because of dementia. Across Norfolk and Waveney there are about 7,000 emergency admissions each year for dementia for people aged 65 and over; this varies by area. The rate of emergency admissions by middle super output area can be seen in figure 6, this shows lower admissions in the North Norfolk area, which may be due to the distance needed to travel to an acute hospital.

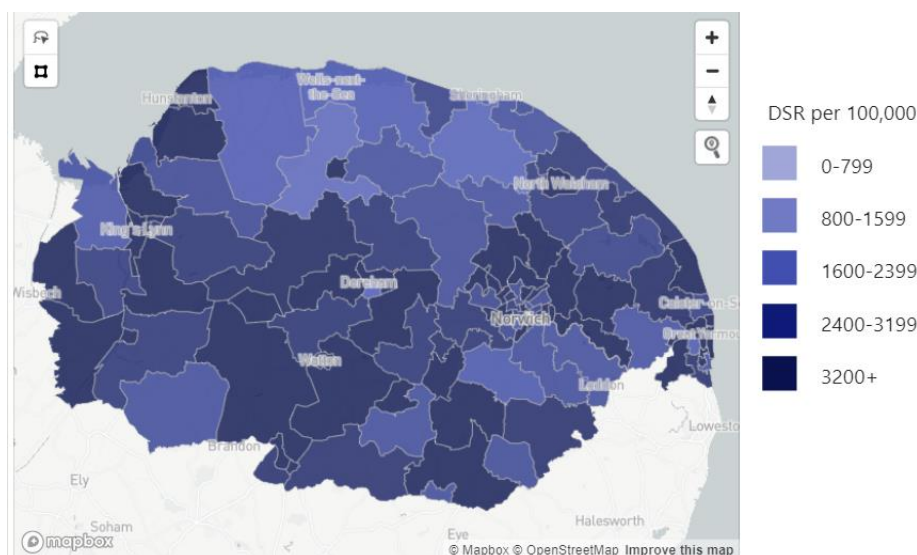


Figure 6. Direct standardised rate of dementia-related emergency admissions (65+) by MSOA. HES, 2018-19.

In Norfolk during the 2019-2020 financial year, 1,225 service users aged 65+ accessed long-term support with the primary support reason being 'Memory and Cognition', the equivalent of 565 per 100,000 people. For people aged 18-64, 75 people were accessing support for 'Memory and Cognition', which is 15 people per 100,000. For the people accessing long-term residential and nursing, this cost a weekly average of £1,037 (18-65) and £659 (65+). In total, Norfolk County Council had a gross current expenditure on both short and long-term care of approximately £29 million for service users requiring support for memory and cognition during the 2019-2020 financial year²¹. In 2020 the quality rating of residential nursing home beds for residents aged 65+ which were rated as either 'good' or 'outstanding' by the Care Quality Commission (CQC) was 62.8% which is significantly lower than the England average of 74.1%. The number of residential care and nursing home beds per 100 persons registered with dementia aged 65+ is 72.5, again this is significantly lower than the national average of 75.3 (for 2020).

Dementia as an underlying cause of death has been increasing steadily each year, with Breckland having significantly higher deaths at 730 per 100,000 than the national average (Fig. 7). In 2010, approximately 500 deaths in Norfolk had dementia as an underlying cause, by 2019 this had risen to, about 1,450 deaths, accounting for approximately 15% of all deaths in Norfolk. By 2025 dementia deaths are projected to make up 18% of all deaths in Norfolk (Fig.8).

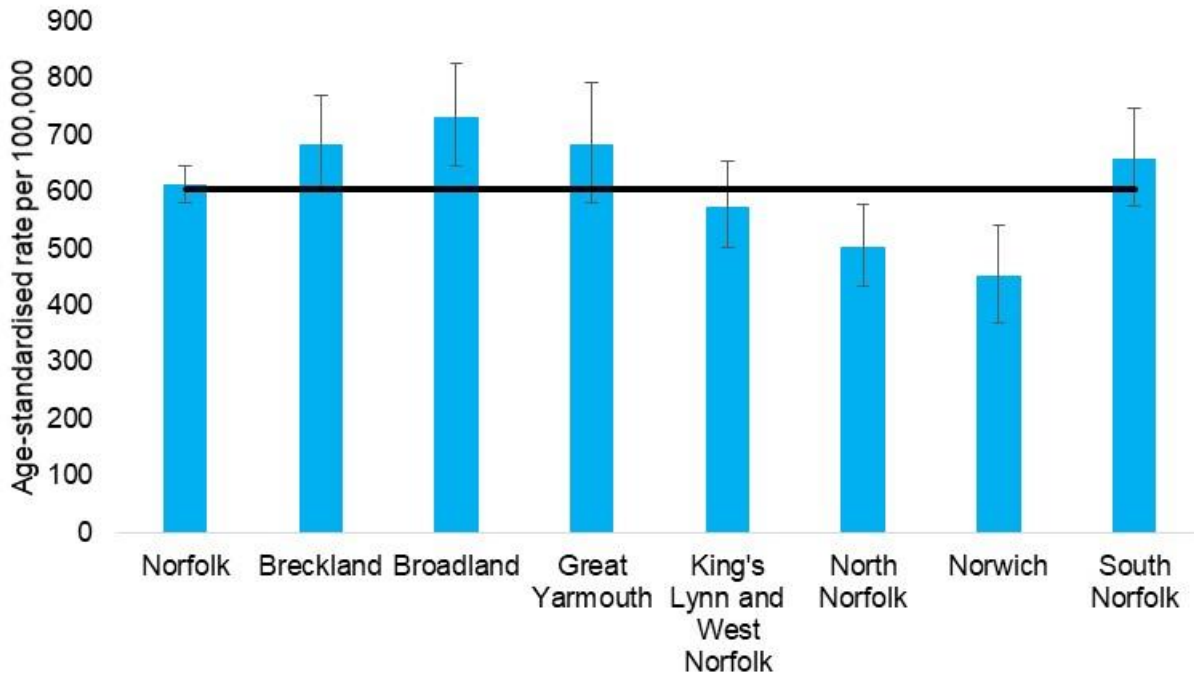


Figure 7. Age standardised dementia deaths (65+) per 100,000 by district compared to England average (light blue line) (2019).

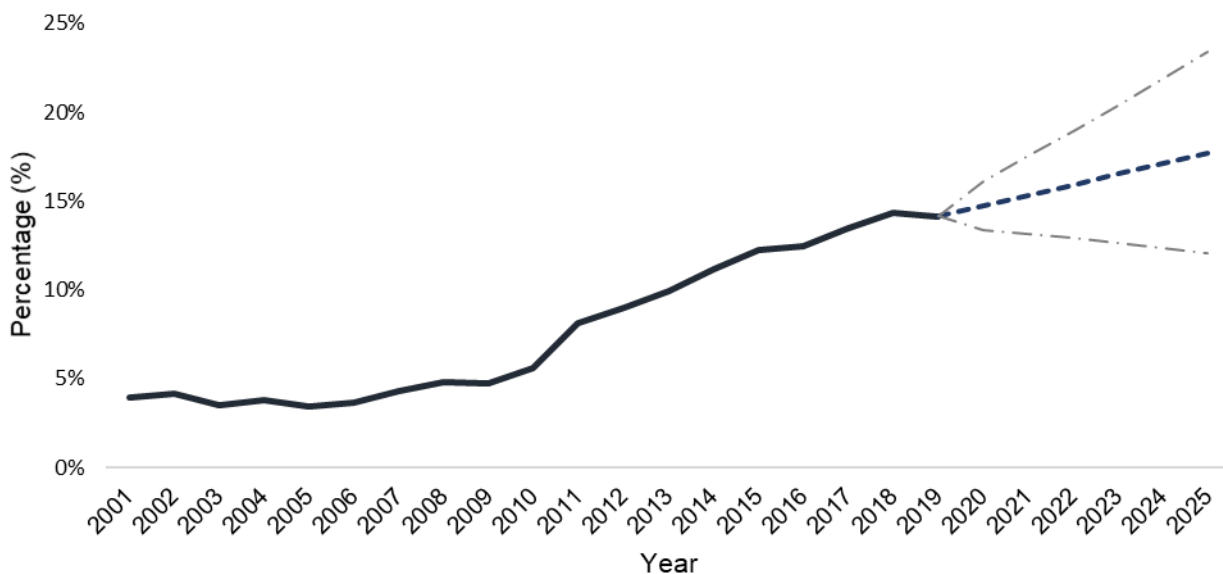


Figure 8. Proportion of all deaths attributable to dementia by year. Middle dotted line shows the forecasted proportion up until 2025 whilst the upper and lower lines are the confidence intervals (95%). (NHS Digital data)

Current services, local plans and strategies

- Nationally, dementia is a priority for both the Government and NHS England. They set out the Five Year Forward View which highlighted the need to upgrade the quality of care and access to dementia services²². They also introduced the 'Well Pathway for Dementia', which is a five-year transformation plan with the aim of better prevention, diagnosis and support for those living with dementia as well as setting standards for living well and dying with dignity.

²² <https://www.england.nhs.uk/five-year-forward-view/>

- Dementia has been championed over the years by a series of partnership groups including; The Norfolk Older People's Strategic Partnership, the Dementia Strategy Implementation Board, the Norfolk and Waveney Dementia Partnership and the Dementia Academy. These partnership groups bring together Norfolk County Council, Norfolk and Waveney Clinical Commissioning Group, the acute hospitals, Norfolk Community Health and Care NHS Trust, Norfolk and Suffolk NHS Foundation Trust, and the voluntary, community and independent sectors²³.
- Norfolk County Council have produced a strategy to change the way they deliver Adult Social Services known as 'Promoting Independence' which aims to remodel services to help people to stay well and live independently for longer²⁴.

Norfolk County Council is supporting the national Dementia Friends campaign by the Alzheimer's Society which aims to change people's perceptions of dementia and the way they think, act and talk about the condition²⁵. Age UK in Norfolk are also rolling out the Dementia Friendly Communities initiative in Norfolk. This was a national challenge set by the Department of Health to help people living with dementia and their carers tackle their day-to-day problems within their community. Wells-Next-the-Sea was the first place in England to have a dementia friendly tourism tip leaflet which provides small simple changes that can help guests affected by dementia to enjoy their stay in which otherwise may be an unfamiliar environment.

It's widely acknowledged that both carers and people living with dementia also require face-to-face support rather than just information online and telephone numbers. There are numerous organisations across Norfolk which provide this provision, including the Alzheimer's, Society, Dementia Action Alliance, Dementia UK, Age UK Norfolk, the Norfolk and Suffolk Dementia Alliance, and Services for carers (see 'References and information' section for links to further information). It's important to remember that if you have any concerns regarding unusual symptoms speak to your GP.

Voice - the perspective from the public, service users, referrers and front-line staff

The Alzheimer's Society produced a 'Dementia Experience Toolkit' following on from a survey that they conducted in late 2018²⁶. This was a survey that involved people with dementia, carers, commissioners, regulators, health and care services providers, researchers as well as dementia organisations and other teams at the Alzheimer's Society. The aim was to produce a more user-friendly website that catered the needs of everyone involved. Some of the key feedback from service users was that they felt staff involved in their care lacked awareness and did not build upon their personal experience of living with dementia and they wanted greater involvement in their care. Meanwhile the staff involved in the care wanted to get better feedback that was accessible and helped shape the services provided. This helped to shape the Alzheimer's Society website available at <https://www.alzheimers.org.uk/about-dementia>.

Alzheimer's Research UK conducted a survey of 2,361 adults aged 15 and over in the UK in 2018. This records the UK's understanding of, and perceptions towards, dementia. It found that over half of the UK public know someone who has been affected by dementia but although the awareness of dementia is increasing that the understanding of the diseases that cause it to remain low. Only a third of people realised that it is possible to reduce the risk of developing dementia compared to 81% who know that it is possible to reduce their risk of developing diabetes. There is however strong public support for research focussed on prevention and cure for dementia²⁷.

Norwich Dementia Action Alliance have been campaigning to improve the experience of people with dementia in cinemas, banks, shops, churches and restaurants since January 2017. To date, more than 100 businesses and organisations have signed up to the alliance and have completed training on how to better support customers with dementia and their carers. This includes initiatives such as hosting dementia-friendly sessions, dementia-friendly signage and working with transport companies to introduce a card system, containing information such as the nearest stop to home and an emergency number.

²³ <https://www.norfolk.gov.uk/-/media/norfolk/downloads/what-we-do-and-how-we-work/policy-performance-and-partnerships/partnerships/health-and-wellbeing-board/reports-to-the-health-and-wellbeing-board/joint-health-and-wellbeing-strategy-2018-22.pdf>

²⁴ <https://www.promotingindependencenorfolk.co.uk/our-practices/>

²⁵ <https://www.dementiafriends.org.uk/>

²⁶ <https://www.alzheimers.org.uk/sites/default/files/2019-05/Example%20project%20update%20dementia%20experience%20toolkit%20Feb%202019.pdf>

²⁷ <https://www.dementiastatistics.org/attitudes/>

Healthwatch Norfolk provides a platform for the people of Norfolk to have their views on the health and social care system heard by the people in charge in order to enable better service provision. It is an independent organisation with statutory powers and therefore the people in Norfolk who make decisions about health and social care have a duty to listen to you through Healthwatch Norfolk²⁸. In 2018 and in conjunction with South Norfolk and North Norfolk Clinical Commissioning Groups, Healthwatch Norfolk a Dementia Friendly GP Practice project was formed²⁹. The guide produced outlined five simple steps for making GP surgeries more dementia friendly and were suggested by local people with dementia and their carers alongside primary care staff and other key stakeholders. These changes were designed to be low cost, high impact solutions to common problems faced by people with dementia. As at March 2019, 4 surgeries had signed up including Sheringham Medical Practice and Wymondham Medical Practice. Initial feedback from the initiative was positive with staff stating that they felt more confident in holding conversations about dementia care and support provided by both the practice and the wider community³⁰.

The Alzheimer's Society conducted research to help understand the experiences of people living with dementia during the pandemic³¹. This subsequently found that people with dementia who were living alone were more likely to report an increase in symptoms and stating that they feel lonelier compared to those who lived with others. Nearly half of people with dementia reported that the pandemic had a negative impact of their mental health with over 1 in 3 reporting that they have lost confidence in carrying out daily tasks and leaving the house. Carers of people living with dementia also noted a strong negative emotional impact of the pandemic with 44% noting impacts on their mental health, 42% noted an additional strain on their relationship with a loved one and 22% left struggling to care for themselves and their loved one.

Useful organisations and support

Age UK Norfolk: <http://www.ageuk.org.uk/norfolk>

Age UK Norwich: <http://www.ageuk.org.uk/norwich/>

Alzheimer's Society: <https://www.alzheimers.org.uk/>

Dementia Friendly Communities: <https://www.alzheimers.org.uk/dementiafriendlycommunities>

Dementia Friends: <https://www.dementiafriends.org.uk/>

Healthwatch Norfolk: <http://www.healthwatchnorfolk.co.uk/>

Norfolk and Suffolk Dementia Alliance: <http://www.dementia-alliance.com/norfolk>

Norfolk Carers Support: <http://norfolkcarerssupport.org/>

Norfolk County Council Dementia Support: <http://www.norfolk.gov.uk/dementia>

Norfolk Older People's Strategic Partnership: <http://www.norfolkolderpeoplespartnership.co.uk/>

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²⁸ <https://healthwatchnorfolk.co.uk/>

²⁹ <https://healthwatchnorfolk.co.uk/report/becoming-a-dementia-friendly-gp-surgery/>

³⁰ <https://healthwatchnorfolk.co.uk/wp-content/uploads/2019/05/HWN-Evaluating-the-Dementia-Friendly-GP-Practice-Initiative-Final-June-2019.pdf>

³¹ [The Impact of COVID-19 on People Affected By Dementia \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/)