

Dementia

Introduction

The number of people over 85 in the UK is predicted to more than double in the next 25 years, from 1.5 million to 3.4 million. Hospitals have experienced increases in the number of emergency admissions of older patients by 18% in the period between 2010-11 and 2014-15. Older patients now account for 62% of total bed days spent in hospital. Promoting active and healthy ageing is essential to reduce the time spent in ill health as much as possible.

There are 850,000 people living with dementia in the UK, costing on average £5,300 to healthcare and £12,500 in social care costs p.a.¹ It is estimated that the annual cost of dementia to society in the UK is £26.3bn¹. With an aging population the numbers of people with dementia is likely to increase and society and services will have to adapt accordingly. Earlier diagnosis and provision of appropriate support will ensure that people will have more choice and control over how they live with dementia and enable them to live life to the full.

Summary

With an aging population the numbers of people with dementia is likely to increase. By 2025 it is estimated that about 18,900 people will have dementia. Patients who have dementia experience many more complications and stay longer in hospital than those without dementia. The proportion of hospital admissions for the over 65s with a comorbidity of dementia is increasing in line with England, reflecting a combination of better coding together with the increasing numbers of patients with dementia.

Together with age, lifestyle factors such as smoking, obesity and lack of exercise and certain medical conditions such as Hypertension can also increase the risk of dementia. This all suggests that for Norfolk the demand that dementia will place on the system 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.

Early diagnosis can help prolong independence for people with dementia and improve outcomes through being able to access support and start treatment earlier. At a GP practice level comparing observed numbers of people with dementia to the numbers expected can give an indication of the number of people who are undiagnosed. Across Norfolk about 57% of people with dementia have been diagnosed.

Dementia is a priority for Norfolk Health and Wellbeing Board and there are various services available for people with dementia and their carers'. However, as diagnosis rates improve, potentially more of these support services will need to be available.

Population, risk factors and outcomes related to dementia pathway

The risk of dementia increases with age and the condition usually occurs in those aged over 65. There are different types of dementia all linked with a decline in functions of the brain. Various mental and personality changes are associated with dementia and these include; memory loss, mental agility, language, understanding and judgement. As the brain changes with dementia it is not only mental and personality changes that occur but also physical changes in such areas as balance, eating, continence and mobility. These changes will impact on ability to maintain independence and everyday activities.

The Alzheimer's Society¹ suggests that there is growing evidence indicating that certain medical conditions - such as high blood pressure, diabetes and obesity - may increase the risk of dementia, whereas a healthy lifestyle may reduce the risk. NICE² show that adopting healthier lifestyles in mid-life can reduce the risk of dementia. For example: give up smoking, be more active, reduce alcohol consumption, eat a healthy diet and maintain a healthy weight. Across the entire life course, educational attainment and social connectedness are protective factors. The above also impact on healthy ageing. So, what is good for the heart is good for the head.

¹ <http://www.alzheimers.org.uk/>

² <https://www.nice.org.uk/guidance/ng16>

The Department of Health's national dementia strategy³ has three key steps to prolonging independence for people with dementia and improving services for dementia patients and their carers:

- Ensure better knowledge about the disease to remove the stigma
- Ensure early diagnosis to improve support and start treatment earlier
- Develop improved services through GP education, having one person responsible for dementia patients in each service provider, helping people to stay in their own homes

The proportion of hospital admissions for the over 65s with a comorbidity of dementia is increasing. Across Norfolk about 10% of admissions have a comorbidity of dementia, in line with the East of England. The increase probably reflects a combination of better coding and information together with the increasing numbers of patients with dementia. Patients who have dementia experience many more complications and stay longer in hospital than those without dementia.

When caring for people with dementia in hospital the Royal College of Nursing found that what is important is:

- Education and training of staff
- Involvement of family carers
- Clear care plan, identifying needs
- Availability of a specialist
- Skilled assessment

The outcomes related to the dementia pathway in Norfolk is summarised in Figure 1

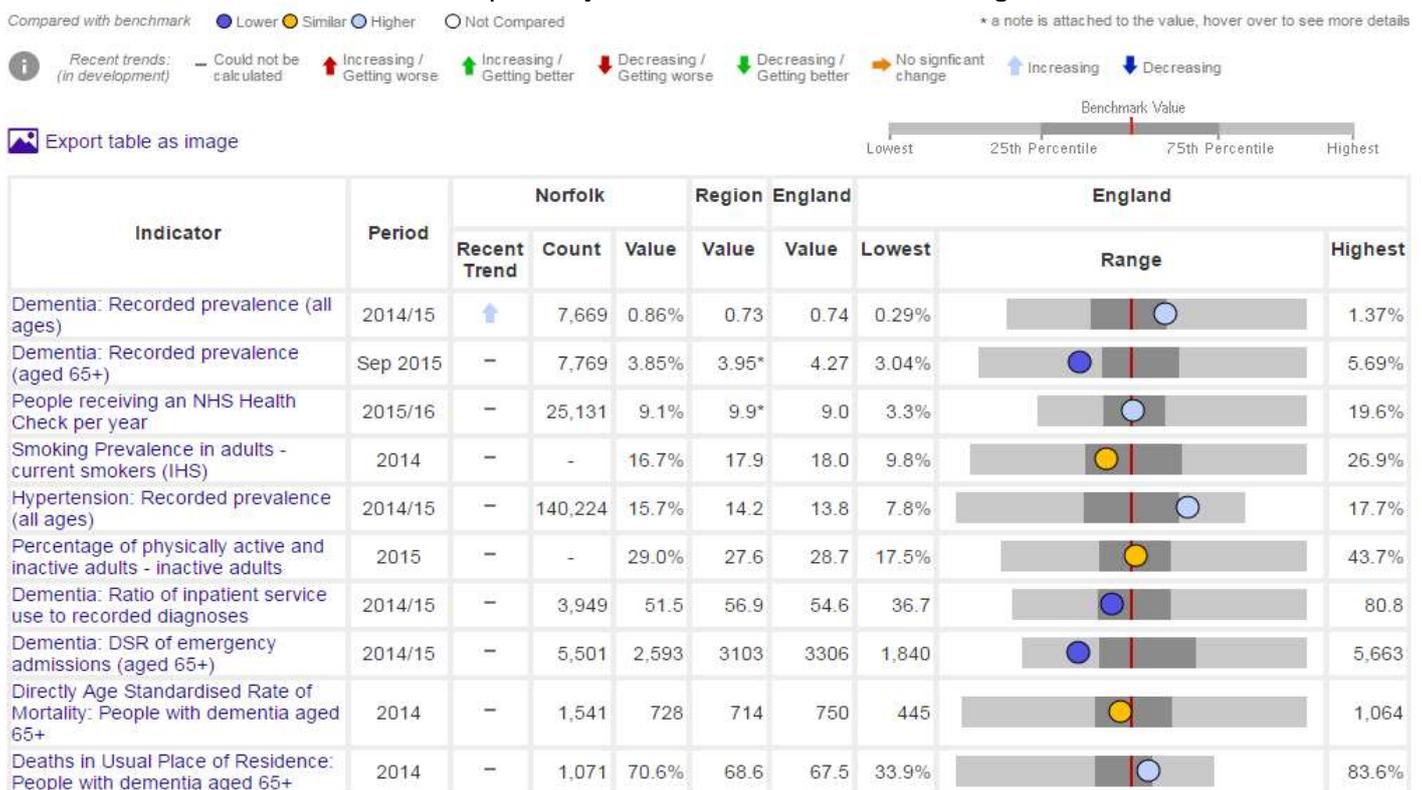


Figure 1 Public Health England dementia pathway summary for Norfolk⁴

Recorded prevalence for all ages is in the upper quartile in the country but recorded prevalence for those aged 65+ is in the lower quartile suggesting that there is still a number of undiagnosed dementia cases. For risk factors for dementia, smoking prevalence and proportion of physically inactive adults are not significantly different to England. However, due to an older population hypertension prevalence is in the upper quartile. This all suggests that for Norfolk the demand that dementia will place on the system 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.

³ <http://www.dh.gov.uk/health/2011/07/dementia-strategy/>

⁴ <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data#page/1/gid/1938133052/pat/6/par/E1200006/ati/102/are/E1000020> accessed 15/11/2016

Burden of ill health and gaps in services

In Norfolk about 0.9% of the population have a dementia diagnosis recorded (Figure 2). This is higher than England and as such will put additional demand on services required to provide treatment, care and support as needed so those with dementia can live well with the condition.

In March 2016 there were about 8,100 people registered at practices in Norfolk with a recorded dementia diagnosis but in 2014 13,900 were thought to have the condition. By 2025 dementia prevalence is expected to increase to about 18,900 people (Figure 3).

For districts within Norfolk the area with the highest number of people diagnosed with dementia is King's Lynn and West Norfolk with almost 1,500 people diagnosed with the condition, about 60% of the expected number of people with dementia (Figure 4). This is estimated to vary across Norfolk from about 24% of people with the condition diagnosed to all the people with the condition diagnosed (Figure 5).

Across Norfolk and Waveney there are only a handful of practices where recorded prevalence is in line with that expected (Figure 6). Further demand is placed on services if people have to be admitted to hospital because of dementia. Across Norfolk and Waveney there are about 400 emergency admissions each year for dementia and this varies by GP practice (Figure 7).

Dementia as an underlying cause of death has been increasing each year. In 2009 there were about 450 deaths attributable to dementia and in 2015 this had increased to 1,200. Overall, dementia is responsible for about 10% of deaths each year.

Dementia prevalence projections for districts and CCGs in Norfolk are shown in Table 1

Area	Diagnosed 2015/16	Estimated Prevalence 2015	Projected Prevalence 2025
NHS Great Yarmouth and Waveney	2,015	3,640	4,782
NHS North Norfolk	1,904	3,365	4,481
NHS Norwich	2,306	2,614	3,284
NHS South Norfolk	1,524	3,727	5,151
NHS West Norfolk	1,744	2,998	3,984
Breckland	1,264	2,197	3,053
Broadland	1,083	2,163	2,921
Great Yarmouth	930	1,519	2,018
King's Lynn and West Norfolk	1,454	2,524	3,323
North Norfolk	1,293	2,283	3,024
Norwich	1,132	1,533	1,820
South Norfolk	961	2,005	2,758
Waveney	1,376	2,120	2,763
Norfolk	8,117	14,223	18,918

Table 1 Diagnosed dementia in March 2016 and expected numbers with dementia for 2015 and 2025

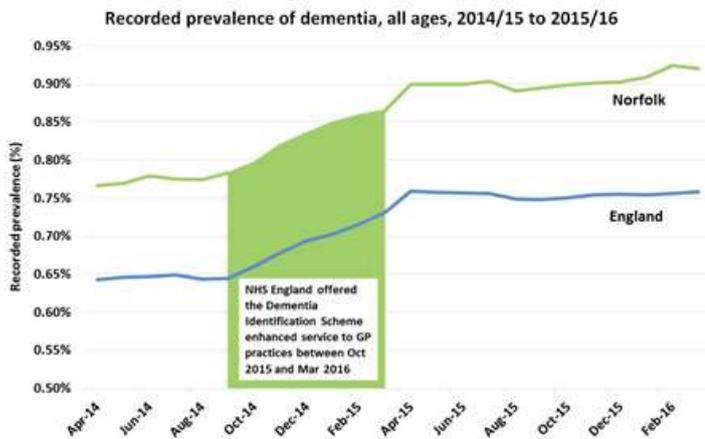


Figure 2 Trend in recorded dementia prevalence by month (NHS Digital)

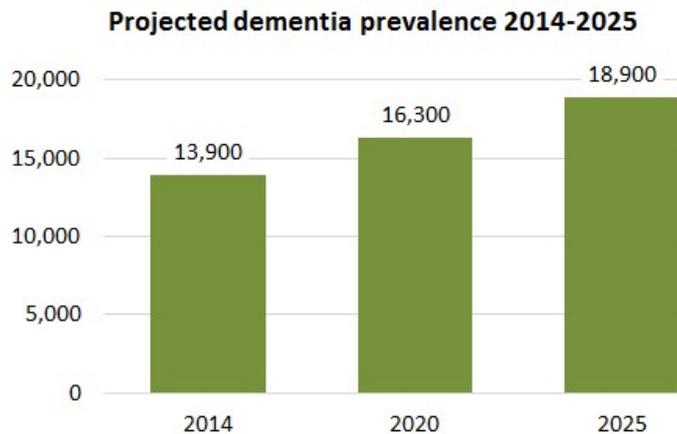


Figure 3 Projected dementia prevalence (CFASII and ONS 2012 population projections)

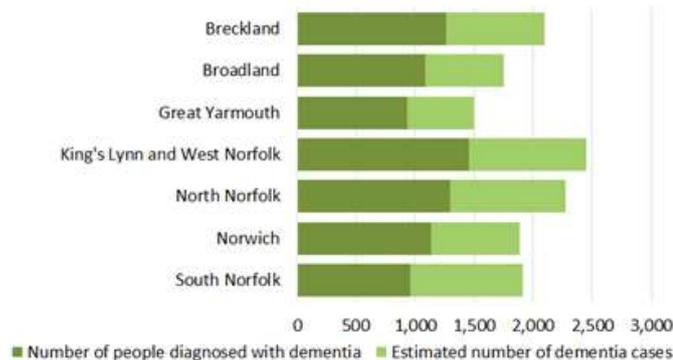


Figure 4 Estimated prevalence of dementia by district 2015

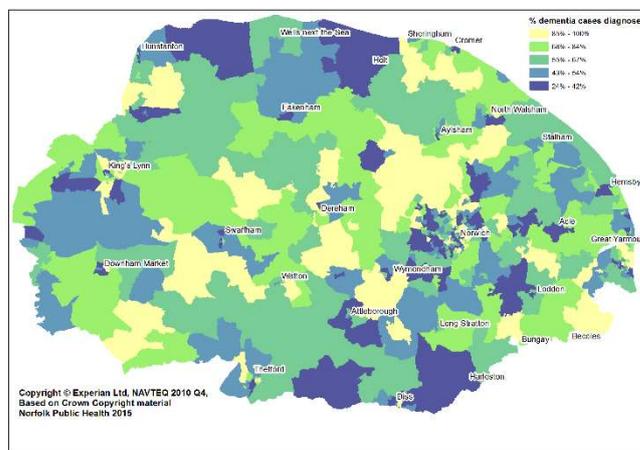


Figure 5 Estimated diagnosed dementia by LSOA 2015

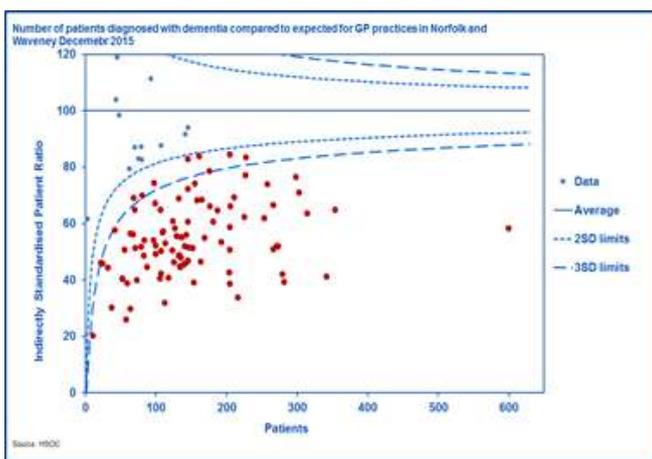


Figure 6 Diagnosed dementia compared to expected for GP practices in Norfolk 2015 (NHS Digital)

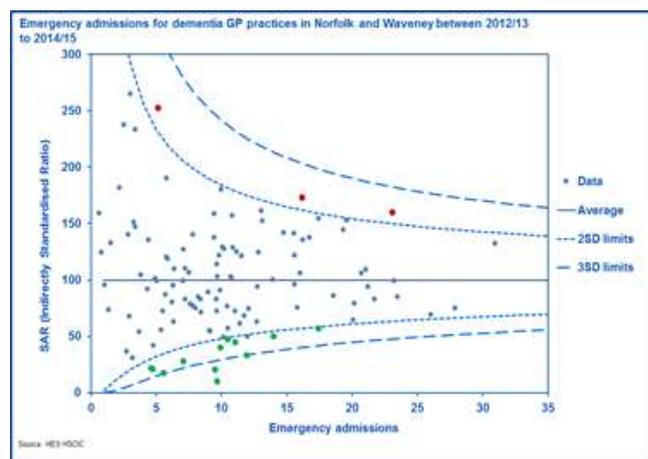
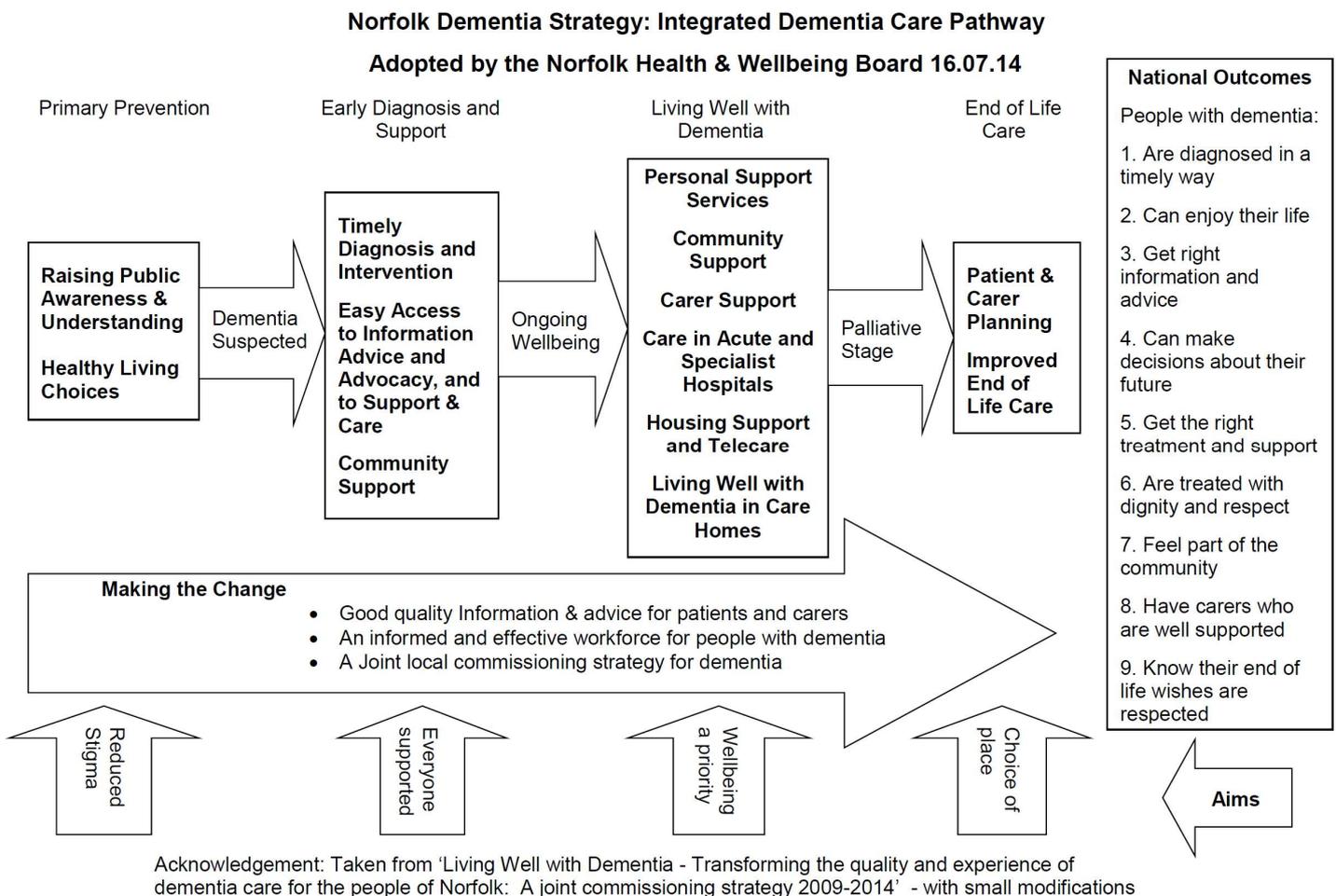


Figure 7 Emergency admissions with a primary diagnosis of dementia for GP practices in Norfolk (HES, NHS Digital)

Current services, local plans and strategies

- Nationally, dementia is a priority in the NHS England Five Year Forward View. This is highlighted through reducing the risk of dementia through addressing lifestyle risks, engaging communities and support for carers and directly in support for those with dementia.
- Dementia is a priority for Norfolk Health and Wellbeing Board⁵. This strategy is being implemented by the Dementia Strategy Implementation Board (DSIB). Chaired by the Dementia Champion on Norfolk's Health and Wellbeing Board, the DSIB consists of senior representatives from across the county including Norfolk County Council, five Clinical Commissioning Groups, the acute hospitals, Norfolk Community Health and Care NHS Trust, Norfolk and Suffolk NHS Foundation Trust, and the voluntary, community and independent sectors. Further information about the work of the DSIB can be found on the NCC [dementia webpage](#).
- Living well with dementia is an integral part of the Living Longer, Living Well Norfolk Older People's Strategy promoting independence and wellbeing through 2016-2018⁶



As expected the current financial climate is putting additional pressures on services but initiatives such as [Dementia Friendly Communities](#) and [Dementia Friends](#) have inspired many to set up support groups, cafes and dementia friendly activities across Norfolk, all contributing to the aim of making Norfolk a dementia friendly county. The role played by the voluntary and community sector is increasingly important but there should be caution around reliance upon it to plug gaps in services.

⁵ <https://www.norfolk.gov.uk/what-we-do-and-how-we-work/policy-performance-and-partnerships/partnerships/health-partnerships/health-and-wellbeing-board/health-and-wellbeing-strategy>

⁶ <http://www.norfolkolderpeoplespartnership.co.uk/>

Norfolk is fortunate to have the [Dementia Friendly Norfolk](#) website. Co-produced with a group of carers of people with dementia this website was launched at the start of 2016, and developed following a recommendation in the JSNA Dementia Needs Assessment 2014 to have one central place for information. The website includes details about dementia friendly events and places across the county such as dementia cafes, support groups and dementia friendly businesses.

It's acknowledged though that people with dementia and carers also require face-to-face support rather than just phone numbers and websites. There are a number of different services available across Norfolk which provide advice, information and support for people with dementia and carers. These include the Alzheimer's Society, Age UK Norwich, Age UK Norfolk, the Norfolk and Suffolk Dementia Alliance, and Norfolk Carers Support (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 Department of Health launched a national [dementia survey](#) on 2nd November to hear the views and experiences from people with dementia, their families and carers'. **The closing date is 31st January 2017.**

The survey is for: any person in England who has received a diagnosis of dementia in the last two years (between November 2014 and November 2016); any person in England who currently provides **unpaid** care or support to a family member, friend or neighbour who has been diagnosed with dementia in the last two years (between November 2014 and November 2016).

The [Public Health England \(PHE\)](#) bulletin published in October 2016 highlights the PHE 'Attitudes to dementia: Findings from the 2015 British Social Attitudes survey'. This paper presents findings on attitudes to dementia in Britain. While the majority of people have known someone with dementia and knowledge of the symptoms of dementia is high, there are clear gaps in public knowledge of the risk factors. There is also evidence of stigmatising attitudes towards people living with dementia.

[Dementia Friends](#) is an initiative launched by the Alzheimer's Society in 2013 to change people's perceptions of dementia; tackle the stigma and lack of understanding that means many people with the condition experience loneliness and social exclusion. There are now over 1.7 million Dementia Friends across England and Wales, who are going out into their communities with a greater understanding of dementia and some of the ways they can help people living with the condition such as being more patient in shop queues, to volunteering, to campaigning for change. A new target of creating four million Dementia Friends by 2020 has been set to create more communities and businesses that are dementia friendly so that people affected by dementia feel understood and included.

In Norfolk there are 20,740 Dementia Friends and 333 Dementia Champions. Dementia Champions are volunteers trained and supported by the Alzheimer's Society to run Dementia Friends Information Sessions in their community and help inspire others to help those living with dementia live well. To find out when the next local Dementia Champions induction is go to <https://www.dementiafriends.org.uk/>.

Healthwatch Norfolk provides a voice for the people of Norfolk. Its' remit is to represent your views and your experiences to help inform and improve the health and social care services that are commissioned and provided in Norfolk. It is an independent organisation but has statutory powers and therefore the people who make decisions about health and social care in Norfolk have to listen to you through Heathwatch Norfolk.

In April 2015 Healthwatch Norfolk published their report [Experiences of accessing information for people with dementia and their carers](#)'. The project captured a snapshot of local people's experiences, focussing in particular on the content, delivery and accessibility of information; asking carers what information they accessed, how they accessed it and who they contacted. Many carers talked broadly about their experiences of dementia services in Norfolk and comments included:

"Well, that it's just knowing who to go to. You know, you just need that one person that you can go to, who can put you in the right direction, to go to all the other things that you need. There's been so many different people that we've had to go to. And so many different things that we've been told, that you just get so muddled up about what you need to be doing and who you need to really speak to. Because they-- everybody will tell you something

different. But you just need one person that you know you can go to, who can sort everything out for you. That is the hardest thing I think I've found.”

“I honestly believe they did not want to give her the diagnosis. Even if you look at it now, it says borderline, which is just so not true. You really felt they did not want to give the diagnosis and that was said to [my sister-in-law] at some point, “well what is the point? What was the point of giving you a diagnosis? How will that help?” There's a part of us that understands that it won't actually make [my mother-in-law's] condition any better but it enables those of us that are caring for her to do a better job. Yeah, there was a huge reluctance to do that.”

Considerations for Norfolk's Health and Wellbeing Board and commissioners

The dementia needs assessment⁷ has grouped recommendations for commissioners into several broad themes

- Information and support for people with dementia and their carers
- Support for referrers
- Making Norfolk Dementia Friendly
- Timely diagnosis
- Planning of services
- Training in addition to the Dementia Friends training
- Integration of services
- Hospital care
- Accommodation and personal care
- Home carers
- Care homes

Given that after July 2017 the new priorities set by Norfolk's Health and Wellbeing Board will come into play it is vital that “making Norfolk better for people with dementia and their carers” continues to be a priority for all. As already highlighted, the numbers affected by dementia across Norfolk are only going to increase. There are approximately 700,000 informal carers in the UK caring for their loved ones with dementia, this is expected to rise to 1.7 million by 2050 (Alzheimer's Association, 2014). This combined with the unprecedented financial pressures on services mean that it is more crucial than ever that we all play our part, and work together to do our utmost to make Norfolk a place where people with dementia and their carers would choose to live.

The **Dementia Strategy Implementation Board (DSIB)** has reiterated the importance of momentum continuing system wide. A particular area of concern highlighted by the DSIB is that of post diagnostic support. The focus and funding has been so heavily weighted on diagnosis rates that the vast area of post diagnostic support has been largely overlooked. Diagnosis rates may have improved but the support services need to be available following diagnosis.

The **Healthwatch Norfolk** report [Experiences of accessing information for people with dementia and their carers](#) highlights that the Norfolk Joint Health and Wellbeing Strategy challenges commissioners and providers to deliver 'person-centred' services:

“Commissioners and providers including voluntary and independent organisations should develop organisational structures, workplaces, processes and referral pathways that encourage joint working and sharing of expertise so that services are person-centred services and duplication reduced.”

Healthwatch Norfolk conclude that “with so many services provided by so many organisations, information advice and advocacy is fundamental to supporting local people to make informed choices about their care. Carers consistently described a preference for highly interactive, face to face, one to one support with a professional, and stated that the provision of high quality, up to date information should be countywide and reach across sectors, localities and eligibility thresholds. In order to deliver an improved quality of life for people with dementia and their carers' in Norfolk, information and advice must communicate a meaningful network of support around the individual, helping them to make decisions about their future and to get the right treatment and support when they need it.”

⁷ <http://www.norfolkinsight.org.uk/jsna/older-peoples-health-wellbeing>

References and information

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

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

Alzheimer's Association: <http://www.alz.org/>

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

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

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

Dementia Friendly Norfolk: <http://www.dementiafriendlynorfolk.com/>

Dementia Friendly employers resources: <http://www.dementiafriendlynorfolk.com/employers/documents>

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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